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ABSTRACT

Ten papers from a May, 1983 seminar on siblings of mentally retarded and developmentally disabled persons are presented. Participants include parents and siblings, and represent a variety of professions including social work, nursing, and psychology. The following papers are included: "Life with an Older Sister" (S. Miller and H. Kalish); "Raising a Family and Dealing with Differences in Children: A Parent's View" (C. Moore); "Normal Siblings of Retarded Persons" (M. Schreiber); "Siblings' Feelings: A Need for Expression" (M. Neel); "Groups for Normal Siblings of Developmentally Handicapped Children" (T. Mates); "Modification of Sibling Interaction in Families with a Mentally Retarded Child" (J. Vespo); "Explaining Differences to Children (J. Giglio); "A Developmental Perspective of the Siblings of Handicapped Children" (J. Feigon); "A Family Systems Look at the Developmentally Disabled" (M. Jaffe-Ruiz); and "The Parent Perspective" (C. Moore). (CL)

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PROCEEDINGS

First Annual National Seminar
Siblings of Mentally Retarded And Developmentally Disabled Persons

Loeb Student Center
New York University
New York, N.Y.

MAY 19-20, 1983

Sponsored As A Community Service By:

Kean College of New Jersey
Special Work Program & Developmental Disabilities Collateral

Association for the Help of Retarded Children
New York City

Mental Retardation Institute
Westchester County Medical Center

New York University School of Social Work

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Program, First Annual National Seminar
Siblings Of Mentally Retarded & Developmentally Disabled Persons

Loeb Student Center, New York University, May 19-20, 1983
Sponsored by
Kean College of New Jersey
Association for the Help of Retarded Children, New York City
Mental Retardation Institute, Westchester County Medical Center
New York University School of Social Work

* * *

Thursday, May 19

8:45 a.m. **Registration, distribution of materials, coffee**

9:30 a.m. **General Session – Eisen and Lubin Auditorium**

Welcome and Introductions
Eleanore Z. Korman, New York University
Helen Murtha, Mental Retardation Institute
Michael Goldfarb, Ass'n. for the Help of Retarded Children
Frank Esposito, Kean College of New Jersey
Theodore DeSantis, Administration on Developmental Disabilities

Presentation of Award to The Association for the Help of Retarded Children for innovation in services to siblings for the past twenty five years.
By the Seminar Planning Comm. to Walter Redfield, Pres., AHRC

A Dramatic Presentation: *Siblings*
Presented by the N.J. Mental Health Players of the Mental Health Ass'n. of N.J.

A Challenge To The Seminar: Why We Are Here And Where We Need To Go
Meyer Schreiber

* * *

10:30 to 12:30 p.m. **Workshop Series #1**

(1) *Developmental Perspectives Regarding Siblings,* rooms 511-513

Chairperson: Richard Stone

Presenters: Gloria Wolinksy, Marion Klutch and Jack Gorelick, "The Needs of Siblings of the Developmentally Disabled: An Analysis of Developmental Needs Over The Life Span"

Judith Feigon and Karen Gronner, "A Developmental Perspective Of The Siblings of Handicapped Children"

Zolinda Stoneman, "Normal Siblings of Developmentally Disabled Persons"

(2) *Being a Normal Sibling: A Developmental Sequence or a Behavioral Deviance,* room 413

Chairperson: Murray Morgenstern

Presenter: Meyer Schreiber, "Normal Siblings of Retarded Persons"

(3) *Explaining Handicapped Conditions to Normal Siblings,* room 408

Chairperson: Helene Geismar

Presenter: Jo Ann Giglio, "Helping Children Understand Difference"

(4) *Siblings Dealing with Institutionalized Siblings,* room 623

Chairperson: Dorothy Gasman

Presenters: Carol Sussman, "A Parents Group Works with Siblings Concerned About the Institutionalized Sibling"

Joseph Spring, "The Institution Reaches Out to the Normal Sibling"

(5) *Extended Family Activities and All the Siblings,* rooms 515-517

Chairperson: Alma J. Carten

Presenters: Esther Ashkanas, "My Family and All My Relatives"

Adin Merrow, "The Foster Child and the Other Child: A Developing Form of Sibship"

* * *

LUNCH – 12:30 to 1:45 p.m. in the Eisner and Lubin Auditorium

During lunch there will be meetings of siblings, parents and professionals in their own separate groups to deal with their ideas and suggestions as a basis for formulating strategies for future activity.

Sibling Convenor: Kathryn Louise Edmundson
Parent Convenor: Betty Pendler
Professionals Convenor: Jack Gorelick

* * *

2:00 to 4:00 p.m. **Workshop Series #2**

(6) *Guardianship and Other Arrangements Affecting Siblings,* rooms 511-513

Chairperson: Terence Gallagher

Presenter: Joseph I. Harris, "Guardianship and Other Arrangements Affecting All Brothers and Sisters"

(7) *Genetics: A Perennial Concern for Siblings,* room 408

Chairperson: Emanuel Chusid

Presenter: Lawrence R. Shapiro, "Multiple Sibling Familial Retardation"

(8) *Developing Sibling Programs in the Community,* rooms 515-517

Chairperson: Nickie Berson

Presenter: Meyer Schreiber, "Tuning Into Sibling Concerns in the Community"

(9) *Parents and Siblings: A Single or Double Standard in Child Rearing,* room 413

Chairperson: Jean Bernstein

Presenter: Cory Moore, "Raising a Family and Dealing with Differences in Children"

(10) *How Siblings, Parents and Professionals Can Work Together,* room 623

Chairperson: Jack Gorelick

Panelists: Esther Ashkanas, Gerri Zatlow and Jack Gorelick

* * *

4:15 to 5:30 p.m.

Dutch Treat Cocktail Party in room 310. Come meet old friends and make new ones.

Friday, May 20

9:30 to 12:00 p.m. **Workshop Series #3**

(11) *Imaginative Audio Visual Presentations Dealing With Siblings,* room 510
Chairperson: Brenda Callaway
Presenters: Fredda Stimel, "Nancy and Scott: A Special Love"
Gerri Zatlow, "The Other Children"

(12) *Work with Groups of Siblings,* rooms 511-513
Chairperson: Meyer Schreiber
Presenters: Thomas E. Mates, Elizabeth R. Willetts and Elaine Goolsby, "Groups for Normal Siblings of Developmentally Disabled Persons"
Marilyn Sheel, "Siblings' Feelings: A Need For Expression"

(13) *Some Current Research Activity Regarding Siblings,* room 515-517
Chairperson: Richard Stone
Presenters: Thomas H. Powell, "Teaching Mentally Retarded Children to Play with Their Siblings Using Parents as Trainers"
Harold Michael-Smith and Murry Morgenstern, "Maternal Attitudes and Reactions of Normal Siblings in Families with a Mentally Retarded Child"
Jo Ellen Vespo, "Modification of Sibling Interaction in Families with a Mentally Retarded Child"

(14) *Utilization of Family Systems Theory and Approaches,* room 413
Chairperson: Lucretia Phillips
Presenters: Marilyn Jaffe-Ruiz, "A Family Systems Look at the Developmentally Disabled"
Selma Miller and Hattie Kalish, "Life with a Retarded Sibling: Two Siblings' Perspectives"

Lunch from 12:15 to 1:50 p.m. in The Top Of The Park, Loeb Student Center

Siblings, parents and professionals will continue their meetings to generate an agenda for current and future activity.

* * *

2:00 to 4:00 p.m. **Final Session – South Lobby** (located on the Main Floor of the Center)
Theme: *Setting a Direction for Current and Future Sibling Activity*
Chairperson: Meyer Schreiber
Presenters: Kathryn Louise Edmundson, Betty Pendler and Jack Gorelick

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Planning Committee

Laurence Goodman
Jack Gorelick

Eleanore Z. Korman
Meyer Schreiber
chairperson

Program Participants

Esther Ashkanas, Parent Advocate, NYC Ass'n. for the Help of Retarded Children

Nickie Berson, Director, Institute for Human Services, Kean College of New Jersey

Jean Bernstein, Dir., Social Work Training, Mental Retardation Institute

Brenda Callaway, Dir., Interdisciplinary Training, Institute for Human Services, Kean College of New Jersey

Emanuel Chusid, Director, UAF Program, Mental Retardation Institute

Alma J. Carten, Clinical Ass't. Prof., New York University School of Social Work

Theodore DeSantis, Region II Prog. Dir. Admin. on Developmental Disabilities

Kathryn Louise Edmundson, The Rockefeller Foundation

Frank Esposito, Dean, School of Education, Kean College of New Jersey

Judith Feigon, Dysfunctioning Child Center, The Michael Reese Hospital & Medical Center

Terence Gallagher, Ass't. Clinic Dir., Ass'n. for the Help of Retarded Children

Dorothy Gasman, Board of Visitors, Letchworth Village

Helene Geismar, Dir., Group Services, 92nd St. YM-YWHA

Jo Ann Giglio, Instructor, Dept. of Psychology, County College of Alleghany County

Michael Goldfarb, Exec. Dir., Ass'n. for the Help of Retarded Children

Lawrence Goodman, Dir. of Social Work, Mental Retardation Institute

Elaine Goolsby, Dir. of Social Work, Div. for Disorders of Development and Learning, Univ. of North Carolina

Jack Gorelick, Dir., Clinic, Ass'n. for the Help of Retarded Children

Karen Gronner, Dysfunctioning Child Center, The Michael Reese Hospital & Medical Center

Joseph I. Harris, The Commission on the Quality of Care of The State of New York

Hattie Kalish, Social Worker, Private Practice

Marion Klutch, Professor, Dept. of Educational Foundations, Hunter College

Eleanore Z. Korman, Asst. Dean for Special Programs, New York University School of Social Work

Thomas E. Mates, Post Doctoral Fellow, Div. for Disorders of Development and Learning, Univ. of North Carolina

Adin Merrow, Medical Dir., Ass'n. for the Help of Retarded Children

Selma Miller, Clinical Psychologist, Private Practice

Cory Moore, Parent Information and Education Coordinator, Montgomery Co. Ass'n. for Retarded Citizens

Murry Morgenstern, Dir., Dept. of Psychology, Mental Retardation Institute

Helen Murtha, Dir., Mental Retardation Institute

Betty Pendler, Parent Advocate, Ass'n. for the Help of Retarded Children

Lucretia Phillips, Assoc. Prof., School of Social Work, New York University

Thomas H. Powell, Ass't. Prof., Dept. of Educational Psychology, Univ. of Connecticut

Walter Redfield, President, Ass'n. for the Help of Retarded Children

Marilyn Jaffe-Ruiz, Chairperson, BSN-NY, Lienhard School of Nursing, Pace University

Meyer Schreiber, Assoc. Prof., Dept. of Sociology & Social Work, Kean College of New Jersey

Lawrence R. Shapiro, Dir. of Genetics, Letchworth Village; Prof. of Pediatrics and Pathology, New York Medical College

Marilyn Sheel, Social Services Dir., United Cerebral Palsy of Greater Louisville

Harold Michael-Smith, Ass't. Dir., Mental Retardation Institute

Joseph Spring, Summit Unit, Letchworth Village

Fredda Stimell, Exec. Dir., Ass'n. for Children with Down's Syndrome

Richard Stone, Ass't. Prof., Dept. of Psychology, Kean College of New Jersey

Zolinda Stoneman, Assoc. Prof., Dept. of Child and Family Development, The Univ. of Georgia

Carol Sussman, Project Director, The Welfare League of Letchworth Village

Jo Ellen Vespo, Dept. of Psychology, The State University of New York at Stony Brook

Elizabeth Willetts, M.S.W. Student, Div. for Disorders of Development and Learning, The Univ. of North Carolina

Gloria Wolinsky, Prof., Dept. of Educational Foundations, Hunter College

Gerri Zatlow, Dir., Siblings for Significant Change

Editor's Introduction

Assembled in these pages are a collection of papers that were delivered at The First National Seminar Dealing With Siblings of Mentally Retarded and Developmentally Disabled Persons. All those persons who presented papers at this unusual educational event were invited to do so, and those represented here responded to this call for papers.

Every effort was made to limit the amount of editing involved and to preserve the original thoughts and language of the writers. As a result, editing was kept to a bare minimum.

What is to be located in this amount of materials is a random sampling of developments in Sibling activity. These articles reveal current interests and concerns and activities of siblings, parents and professionals. They attest to the rich source of materials regarding the human condition that is to be found in Sibling activity. The papers mirror the state of our knowledge and research and reflect themes that need to be used as building blocks for the future.

These contributions, however, do not in any way tell of the enthusiasm and excitement generated by the 225 participants from all parts of the country who came to Loeb Center, New York University, to talk and to listen, to question and to learn, to share and to wonder in an atmosphere marked by a community and mutuality of interests. For many it was the first opportunity made available to them to discuss their own experiences as Siblings, or to discuss Sibling interests and concerns, with a host of other people who were similarly committed.

A debt is owed by all of us who ponder this material to the board and staff of the NYC Association for The Help of Retarded Children who responded to an inquiry from Kean College of N.J. to develop this seminar. In a similar fashion, the Association made available a grant to facilitate the issuance of these proceedings. All of us are thankful and grateful that the Association did so.

The best measure of the interest generated by a human event is its continuity. Already the Second Annual Sibling Seminar is a reality for June 1984.

Meyer Schreiber, DSW, Editor

TABLE OF CONTENTS

Page

EDITOR'S INTRODUCTION..................................

Meyer Schreiber, DSW, Assoc. Prof., Dept. of Sociology and Social Work, Kean College of NJ, Union, NJ.

1. LIFE WITH AN OLDER SISTER.............................. 1

Selma G. Miller, Ed.D., Clinical Psychologist, Private Practice, New York, NY.

Hattie Kalish, MSW, Social Worker, Private Practice, Philadelphia, PA.

2. RAISING A FAMILY AND DEALING WITH DIFFERENCES IN CHILDREN: A PARENT'S VIEW............................ 6

Cory Moore, Parent Information and Education Coordinator, Montgomery Co. Assoc. for Retarded Citizens, Rockville, MD.

3. NORMAL SIBLINGS OF RETARDED PERSONS.................. 14

Meyer Schreiber, Assoc. Prof. Dept. of Sociology and Social Work, Kean College of NJ, Union, NJ.

4. SIBLINGS' FEELING: A NEED FOR EXPRESSION............ 34

Marilyn S. Neel, Social Services Director, United Cerebral Palsy, Louisville, KY.

5. GROUPS FOR NORMAL SIBLINGS OF DEVELOPMENTALLY HANDICAPPED CHILDREN................................ 43

Thomas Mates, Post Doctoral Fellow or Psychology, University of North Carolina.

6. MODIFACTION OF SIBLING INTERACTION IN FAMILIES WITH A MENTALLY RETARDED CHILD....................... 54

Jo Ellen Vespo, Dept. of Psychology, The State University at Stony Brook, Stony Brook, NY.

7. EXPLANING DIFFERENCES TO CHILDREN.................... 64

JoAnn Giglio, Instructor, Dept. of Psychology, County College of Alleghany County, PA.

TABLE OF CONTENTS

(Continued)

Page

8. A DEVELOPMENTAL PERSPECTIVE OF THE SIBLINGS OF HANDICAPPED CHILDREN.................................. 69

Judith Feigon Social with Supervisor, Michael Reese Hospital, Chicago, IL.

9. A FAMILY SYSTEMS LOOK AT THE DEVELOPMENTALLY DISABLED 79

Marilyn Jaffe-Ruiz, PhD, Chairperson, BSN-NY, Lienard School of Nursing, Pace University, New York, NY.

10. FINAL SESSION: THE PARENT PERSPECTIVE............... 94

Cory Moore

LIFE WITH A RETARDED SISTER: TWO SIBLINGS' PERSPECTIVES

1. The Older Sister - Hattie Kalish

When I ask myself what did it feel like to be the older sister of a retarded child, I think of disappointment, anger, frustration, fear, embarrassment, guilt and hopelessness.

I remember at age eleven, the excitement of the prospect of having a sibling. My brother, four years younger than I, died when he was four and I was eight. I looked forward to having another brother or sister. It had been lonely being an only child again, and I welcomed the idea of a baby who would grow up to be a playmate. My sister Frances was a beautiful, blonde-haired blue eyed little girl, and I watched her grow and was so happy that when I went to overnight camp it was Frances that I wanted to see first when I came home.

When Frances was three or four, the disappointments began. Frances didn't talk, she didn't play with other children, she couldn't go to school but went to "speech class". Her progress was minimal and she didn't catch up to the others. My parents looked worried, they didn't talk to me about Frances, but they kept talking to doctors. Initially it was said out loud, "Frances is retarded" the household was gloomy, my parents were sad. Gone were my hopes of a playmate for companionship and fun. I felt cheated, disappointed and then angry. This was another, different kind of loss. I wasn't going to have a normal sibling. I realize now that I must have promised myself then, that I would never get attached to another child. When my sister Selma was born, I began to keep my emotional distance. I wasn't going to take a chance again.

As I grew into adolescence I brought friends home from school. Boys came to call to take me out on dates. I was so embarrassed. The beautiful little girl now had a foolish look on her face. She asked each visitor the same questions over and over "What is your name," "what floor do you live on." I didn't want to admit that she was retarded -- my parents told people she was a little slow -- I said Frances liked people. I wanted to hide my sister. I was ashamed; angry that she was different, and furious when my parents occasionally asked me to take care of her. And then I felt guilty. My parents kept saying that Frances was "cute", "pretty", "appealing". She didn't seem that way to me. Then I would feel that I must be a horrible person, but the feelings of anger, frustration, shame, and embarrassment were too strong to go away. I would feel angry at my parents for the guilt they induced in me; angry with myself that I couldn't see her as they did. I would be furious that they always excused her when she misbehaved. When she crunched chicken bones, when she passed gas with a loud bang, when she took my prize possessions from bureau drawers and pocketbooks, it was always the same; "She can't help herself," or "she has so little pleasure, can't you let her do what she wants."

Now, fifty-three years later, many things have changed. We can admit when there is a retarded child in a family, without trying to hide that fact. We can say that retarded children aren't appealing just because they are retarded, that they and their families are happier, if they are helped to understand what acceptable behavior is, and helped to achieve it, within the limits of their abilities. It's alright for older sisters to feel angry with younger siblings even if they are retarded. Those feelings that are openly expressed don't build up to volcanic proportions.

I'm very happy to have overcome my fear that having children of my own was too risky -- that they would be sick, or handicapped, or retarded.

I'm happy that I can accept Frances as my sister without anger, or embarrassment, that I can see her sweetness, and stop worrying over only her handicaps, as long as she seems contented.

I'm so happy too, that I finally permitted myself to love my sister Selma in spite of my fears of loss.

The world is different now for retarded people and their families. There are parents groups, recreational programs, schools for retarded children and seminars like this on what it means to be a sibling of a retarded brother or sister. We know more about some things that cause retardation, and something about how to prevent it. I feel good about how I have changed and how the world of the retarded person has changed and continues to change due to the efforts of all of us.

2. The Older Sister - Selma Miller

As usual Hattie finished writing her presentation for you long before I had even started to formulate my thoughts and also as usual I was impressed with the job that she had done. I guess I will never know if what Hattie can do is better than what I do or whether a younger sister never feels she can quite catch up to an idealized older sister.

Perhaps that colored my attitude toward Frances for many years. I knew from a very young age that life with Frances meant that I would be safe from the competition that I felt with Hattie. I could wash and take care of myself, Frances could not. I could read and spell and do arithmetic, she could not (or at least not as well as I could). I could go to the park and play with other children and she could not and perhaps most important of all I could communicate my needs, my fears and my thoughts without kicking and screaming. In fact I was so much more capable than Frances that I really didn't need to work at school to stay ahead. What was the use, I wouldn't ever catch up to Hattie and I had all the head start I needed to be ahead of Frances. Occasionally people have suggested that I felt guilty and therefore prevented myself from getting good grades or that I was angry and resentful but these are only words, they only make sense on an intellectual, not an emotional level. In return for my feelings of superiority and power it seemed to be more than fair that my parents and governess expected me to return the advantage by being very grown up.

My very first memory is of a trip that the family took to Colorado Springs when I was 3 years old. My mother, my governess, Frances and I were down by the swimming pool. I remember Frances coming over and biting me. I started to cry. My mother came over and explained to me that Frances did not understand what she was doing, she couldn't help herself. She told me that I was a big girl and could understand. How proud I felt my mother had said that I was able to do something that my bigger sister (Frances is over 2 years older than I am) couldn't do. That moment set the stage and probably determined my attitude for the rest of my life. I was lucky and Frances wasn't. I needed to take care of her and protect her from people that didn't understand her the way that I did. When children teased her I became indignant, didn't they understand that Frances was unable to take care of herself? Why did they stare at her and make fun of her? They should be kinder. I didn't want to play with them, they weren't nice. Many, many years later when I was grown I started to admit to myself that I got angry when people stared at Frances because it made me feel uncomfortable. I felt that there was a stigma attached, not to Frances, but to me as well. Of course, by then I could understand what it meant to be stigmatized. In addition to protecting Frances, I had to do all I could to act grown up. Being grown up meant not crying, taking care of myself and most important of all being very patient with Frances. She frequently lost control and screamed, yelled, lay down on the floor, kicked and continued to bite and pinch. I remember many mornings waiting with my hat and coat to go out while the entire household tried to control Frances. When she was calmed down we went out. It's hard for me to convince anyone that this situation was not slightly short of a horror scene, but it wasn't. To me it was a part of my life and I accepted it without being aware of any emotion. I thought my childhood a happy one.

Around the time I was nine Frances was sent away to school - I was told by my mother when I was in my twenties that they felt that it would be better not to have Frances around when I entered adolescence because boys might be afraid to come to date me. I appreciated this concern and never told them that this ushered in unhappy and lonely years. I missed the excitement. The house became stony quiet. Hattie got married and moved to Philadelphia. Her friends no longer came. My mother and father were older and emotionally worn out. Hattie tells me that even my father, who was a jovial outgoing man, just wasn't the same. The death of a son before Frances and then having a retarded child was too much, even for him. I looked forward to visiting Frances at school, except that she screamed for us to take her when we left to go home. Those screams still echo in my mind and make me sick. I begged my parents to bring her home and when that didn't work I begged to be left with her. Life in those schools wouldn't be bad. I wouldn't be lonely, the other kids always liked me. I would be secure again in a safe environment and I wouldn't have to leave Frances behind. I prayed they would leave me. They didn't. I knew how upset my parents were and there was nothing I could do except one thing: I could promise them that someday when I was older and they were no longer alive I would never, never send Frances away from home. My mother was so relieved she would ask me about this over and over again, and it helped so much to know I could make her feel better. It also made me feel less guilty and, most important of all, in the rapidly deteriorating relationship between my mother and me, it was the one thing I could do or say that made me feel that she still loved me.

Frances remained away at school until I was 19 years old. The reason I remember exactly when she came back is because that was the year I became engaged. It would be safe, I guess, to have her around. Years later I realized that my parents had reason for concern when I learned that my husband's parents had spoken to doctors in order to reassure themselves that Frances' illness would not be passed on to their future grandchildren. It made me angry then, but today I can accept and appreciate this concern.

When Frances returned home things were very different. I was no longer accepting of the fact that Frances needed to do whatever she wanted. I had become in touch with the fact that it wasn't good to condone any and all behavior. I likened the situation to Helen Keller and I saw myself as Ann Sullivan. Of course that didn't work out too well as Frances was 22, I was still her younger sister, and, perhaps most important, I was long on ideas and short on patience. I did, however, manage to stop her from biting or pinching me and I knew she would never do it again. When people asked me how I could be so sure when she was still doing this to my parents, I told them that Frances knew when someone really meant what they said, and I meant it. Unbelievable as it may seem I still did not feel anger towards Frances. My anger was directed at others. How can you be angry at someone who is helpless? At someone that is never mean? And most important of all at someone that you were told needed your help because you were luckier than they? The answer is that you can if you are allowed and are taught that caring, concern and love does not preclude anger. That people are capable of many emotions about the same person and a retarded individual does require more time, more attention and frequently acts in antisocial ways. To make believe that this does not affect other siblings is nonsense.

During the years that followed Frances' return home there was a gradual shift in responsibility from my parents to me. Hattie was, and continued to be, always there to talk to me, to listen to me and to help in whatever way possible. But she lives 90 miles away and it was always assumed by both my parents and me that because of our early years together and my role with Frances that I would take care of her when my parents were not around. Once again I accepted this completely and fully and still do. However, there is nothing anyone could have said to me to have prepared me for the feelings that surfaced 1 1/2 years ago when my mother died. I had raised 3 children of my own, gotten a doctorate, had a successful career. Certainly I was not afraid of responsibility. I still have not sorted out what makes the situation with Frances so different. I am lucky that my parents have provided for her so I don't need to be involved with the day to day care. I have lots of thoughts but no answers. I know that I can be much more understanding of some of the feelings my parents must have had and I certainly am much less definite about what is right and what is wrong: (A feeling most parents have at some point raising any child). I also know that for me it is critical to have interaction with other siblings of the retarded. There is a sense of tremendous relief when I try to sort out a tangled feeling or emotion and someone says "I think I know what you mean" and then shares a thought or an incident that helps to put another piece in an enormously complicated puzzle! It's a connection you can only make with someone who has had a similar experience. I realize that the sibling conference today is the First Annual Seminar on siblings of mentally retarded and developmentally disabled. I feel that the opportunity that this provides to me, my sister and others like us is extraordinarily valuable. We are no longer separate and alone. There is the comfort of sharing and talking to others that speak the language. Communication is essential to our existence and this is now possible for siblings of the retarded.

RAISING A FAMILY AND DEALING WITH DIFFERENCES IN CHILDREN: A PARENT'S VIEW

Cory Moore

I speak to you with the knowledge and feelings of a parent, not a sib. I'm also a self-made, or -- more accurately -- child-made, professional, one of those fortunates who, because of good genes, a great education.... and several years of intense therapy, have weathered the "fivestagesthatallparents-ofhandicappedchildren" go through (recognize those?) and am in that final stage where I can share and help without screaming, "UNFAIR!" -- at least much of the time. I must admit, it's pretty easy to be in the final stage 300 miles away from the source of my knowledge, although, standing here, I'm impressed with what this parent will take on to get some respite! At any rate, although I'm not an expert on sibs, as the mother of three children including a multi-handicapped teenager, I'm intimately acquainted with two who are. I'll be drawing on their experiences as well as the observations of several others in the parent and sibling literature on my topic.

First, an introduction to part of my family -- Leslie, her sister, and her brother. Leslie is the middle child, 18 years old, tests in the mild to moderate range, about a 55 IQ but genius level in social manipulation, non-ambulatory, uses a wheelchair, and has a now-happily-medication-controlled migraine condition. Laurie is 20, at the moment a college-dropout (the silliness of labels!), a life-liver, partaker of EST-- the training that transforms your life, writer, dancer, a West Coast breakthrough consultant and transformation helper who nurtures her clients by giving them "unconditional like." And Kenny, 15, who recently described himself as "the only one in my family who is normal." Indeed, he had to be! He's a member of the school band, an SAT worrier, in general an all-around good kid.

On to dealing with differences within a family.

In a family like mine, where children are inherently not equal, neither the expectations of the handicapped child nor the demands placed on that child can be equal. This, then, leads parents to a double standard in child-rearing: one set of rules -- or nonrules -- for the child with the handicap and what may be perceived in contrast as overwhelmingly unfair demands on all the others. They are not, after all, adults with understanding of "why" things are, or are not, expected.

Every day, brothers and sisters of children with handicaps deal with the difficult family message that expectations are quite different for them. Hear Louise Wilson in THIS STRANGER MY SON in an extreme "for instance":

> we were rearing two families. There was one set of rules for Tony, and another for Jane, Sarah, and Freddy. The three were required to wash their hands before dinner, to sit up straight at the table, to speak respectfully. Tony slouched and spilled and thrust his dirty hands into the mashed potatoes, but no one said anything about it. We were thankful, we thought the evening a success if only he kept the peace and left everyone alone. This standard made sense for Tony; first things first, and the first thing was to put him at ease and never mind the dirt. But making that clear to the other children was difficult indeed. All they could see was the unfairness.

Deppe and Sherman comment in THE HIGH-RISK CHILD:

> Many parents tend to be easier on the special child than on other members of the family. The difficulty of communicating with the special child sometimes forms a barrier to understanding... Parents are in many instances more willing to give in than to consistently reinforce the desired behavior. Not only can this create the existence of a real double standard, but a wave of resentment can easily be formed.

They quote a parent:

> For one thing, the kids were not that much older than he was, and they did not understand that our discipline... well, they accused us of having a double standard of discipline. Discipline for him and discipline for them. The one that was closest to him gave us the most trouble. You know the "he can do that, and I can't" sort of thing. "He gets a lecture, I get a spanking." That really got to us, it really bothered us, because we didn't know what to do about it.

To a young child, the exemption of the retarded child from demands and expectations is seen as parental favoritism. Further, time and attention from parents equals love. An English mother speaks:

> The one that Evan [the retarded child] has hurt the most has been Ruth [age 5] because Ruth, being a baby, whenever something happened to Evan, she was pushed aside... It grows on the youngster's mind, why is he getting it when he's older and I'm still a baby and I'm not getting it? Things just don't go that way, now do they? And I feel that she will always have that in the back of her mind, because even now she gets a little resentful at times when Evan does

> something that he's got to have my attention for quicker than hers. And it's just like with potty training. Ruth feels: well, he's older; why isn't he potty trained. Why do I have to be when he's still older than I am? Why do I have to do everything before he does when it comes to learning things? But then, on the other hand, why does he come before I do? So I mean it's quite confusing to her and I feel that Ruth feels it more than anyone else.

Kenny Moore:

> The double standard I live with is like a bell-shaped curve. When I was young, of course, I didn't really notice. When I got older, like in fights, it seemed like Leslie always got her way. My friends are always amazed at the privileges Leslie gets over me.

He's right, of course. It has often been anything for peace; the "fights" he refers to inevitably start at the very end of a day. (Now that Kenny is close to 16, with several car-driving friends, the other end of the bell-shaped curve is most understandable.)

Should a disability excuse provoking behavior? Without even suggesting an answer, let me share some of my family anecdotes. Understand that the point of view as to how behavior should be handled and how it is handled differs from one generation's point of view to another.

> [1. Car ride... "I really not want you in my family." "MOTHER!"
> [2. He a baby, he acting just like one!" "And how are you acting?" "A little after one?"]

I laugh. I repeat the story. Kenny doesn't think it's so funny.

> [3. "I really miss hearing you play the flute." "I really unmiss hearing you play the flute."]

Again, a parent smile, a sibling hurt.

Additionally, even in the most helpful of families, there is often unspoken understanding -- often accurate -- on the part of the nonhandicapped sibling that he or she must be a child and-a-half to make up for the handicaped sib, that often he or she plays the role of miniature parent, that his or her own needs are neglected.

Sibs must understand far beyond their years. The mother who worried about Ruth, the baby, speaks of her seven year old daughter:

> Well, just like I've told her with this here pushing habit that Evan gets into, I said whenever Evan pushes you, turn around and push him right back, -- just make sure he doesn't get hurt. I says don't push him into the wall or onto the bookcase or bang his head into a cabinet or something. I says just push him.

Would you dare?

Sometimes, particularly in the early years, parents are often obsessed; Maureen Lynch writes of an adult talk with her mother in her book MARY, FRAN AND MO. Lynch's reaction to the conversation is not recorded. Her mother is speaking:

> . . . one of the first times I thought we might be able to help her was when I read about a clinic in Philadelphia that had developed something new, something they called patterning. She was only four, it might have helped her. Maybe not. But [your Dad] said I was being ridiculous that I couldn't go flying out East when we had three other children."
>
> "Yeah, I've read about that clinic," I said. "But what were you going to do with me? If Fran was only four, I was two-and-a-half."
>
> "I didn't really think about you," she said. "Anymore than I thought about Patricia or Philip. I just knew that she needed special help. I thought maybe they could give it."

Now hear of the parts played by non-handicapped sibs. The first is Robert Meyers who wrote LIKE NORMAL PEOPLE.

> My role in those days was someone who was always around to help care for Roger. That was my mother's phrase. My father called me his "good right arm." Roger himself called me "Dad" before he corrected himself and called me "Bobby."...
>
> I never felt I dressed like a kid, never felt comfortable with the clothes I wore, never felt I knew how to act as a boy or a teenager. I was a little man.

Listen to Victoria Hayden, whose younger sister was deaf.

> When Daddy spent a year in Korea, I became Mother's sole helper. My role as second mother to Mindy held some prestige and much responsibility.... And, just as a mother serves as an example for her children, I was expected to be an exceptionally "good" little girl. The high standards my mother set for my behavior, though, had not only to do with my setting an example; her reasons were also practical. Mindy's impetuous behavior left her with little patience, energy, or time to put up with shenanigans from me....

> The responsibility I felt for Mindy was tremendous. One year, when my "babysitting" duties involved periodic checking on my sister, Mindy wandered away between checks. After a thorough but fruitless search of the neighborhood, my mother hysterically told me that if anything happened to Mindy I would be to blame. I felt terrified and guilty. I was seven. [THE EXCEPTIONAL PARENT, August 1974]

Families are intricate and complex, different and yet in some ways the same. Every child want and deserves to be special inside his family. A disability may be seen as a distinct advantage. The small gain of the "special" child (note the word; what child isn't special?) seems often to be more valued than the significant accomplishments of the nonhandicapped sib. Helen Featherstone, in her marvelous book, A DIFFERENCE IN THE FAMILY, the definitive work on raising a handicapped child, quotes from an unpublished doctoral study:

> At one point, Mrs. T. was remarking that she "didn't feel that the children had any trouble dealing with Lucas," and I noticed Cindy quietly shaking her head on the other side of the room. I decided to pursue her silent dissension when the parents had left. I thought that I might help Cindy out by asking about her quiet disapproval when her mother had been speaking. She was silent for a few moments, then said in a low voice: "I think Mama's wrong. I mean, I can remember a lot of times when I couldn't do the things I wanted or have them see that I could do things like.... Well, there was this one time when I got all A's on my report card. All A's! That's something for me. Anyway, I came running through the front door and Mama was all excited so that I thought she already knew. Well, it turned out that Lucas had said his first word, and Mama was so happy. So, I said, "Mama, I got all A's, I got all A's." And she said, "Oh, that's nice. Guess what? Your brother said so-and-so today." And went on and on about it. But I didn't say nothing. But that really hurt me, you know?"

Victoria Hayden, again:

> Mindy's achievements always met with animated enthusiasm from our parents. In contrast, it seemed Mother and Daddy's response to my accomplishments was on the pat-on-the-back level. I was expected to perform well in every circumstance. I wanted my parents to be enthusiastic about my accomplishments, too. I didn't want to have to beg for praise. I didn't want to be taken for granted. I wanted to be noticed.

And the adult Robert Meyers, still smarting from all the years of having his brother's needs come first and angry because his parents did not read of his significant newspaper reporter accomplishment, cries out:

> What is it I have to do to get you to pay attention to me?....This involves the President of the United States -- would you read about me if I had investigated God?

What the children may not see in the growing up years are other parental feelings. From CARA: GROWING WITH A RETARDED CHILD by Martha Moraghan Jablow:

> Sometimes I find myself wondering if I favor David [the non-handicapped child]. His sharp sense of humour, his ability to observe and absorb every detail.... and ask bright questions delight and amaze me.... I think of David's future as bright and unlimited.... This is hardly how I see Cara's future.

Robert Meyer's mother:

> I worried about you, about the effect Roger was having, would have on you. You were a part of the family; we needed you to help with Roger, but even just worrying about what effect it was having on you tore me up.

Sometimes when families are aware, there may be ways of helping children to understand better. Bette Ross in OUR SPECIAL CHILD tells of a friend who rented a wheelchair so her son Ricky, seven, could spend the day in a wheelchair, too, along with 5-year-old Bobby who had cerebral palsy. Both boys enjoyed themselves. But then Ricky needed the bathroom; his mother refused to let him out of the wheelchair to go by himself. He endured the embarrassment of being helped. Ricky wasn't allowed out to play with a friend since the agreement was to be like Bobby for the whole day. Ricky never again complained about how much time his mother spent to help Bobby. In time he became a willing helper himself -- or so the story goes.

In addition to aiding non-handicapped children to gain awareness, parents might also profit by listening to the unique perspective of the sib. In a family discussion about discipline, when a friend was taking a stand on the side of lower expectations, she was told most emphatically by her teenager, "I know better than you, Mom. After all, I've lived with Susan ten of my 14 years; you've only known her ten of your 46 years!"

I share briefly one more double standard; one set up by the society in which we live. In my town, children who carry the label of moderate, severe, or profound retardation go to segrated alternative centers from the time they are babies until they graduate at age 21. Truly a double standard. A message to parents and sibs alike of separation, devaluation, isolation. Maureen Lynch remembers:

> Then came the question that I always hated: "What grade is she in?" Sometimes I would muster all my bravado to try to

make it sound like I was sharing my wisdom with someone who was hopelessly out of it. Other times I would just mumble my way through the sentence, just wanting to get it over with: "She goes to the special school, they don't have grades."

A message to the retarded child as well, who most certainly does not always profit from the handicapping condition, contrary to what sibs may feel: Elizabeth Pieper in LET OUR CHILDREN GO by Biklen:

> In the beginning of the summer, when Julie's friends come in groups, excitedly savoring their freedom, and she leaves with them, Jeff chokes up and his eyes redden with the strain of holding back tears. Sometimes he bursts out crying, but softly, when I ask what is wrong. Usually he says he is "sick" or points to his head saying he has a headache. For a kid with a 35 I.Q. he is uncommonly perceptive. He feels my own indaquacies -- and my pain. He is being kind to me, but is a poor liar. We both know what is "wrong." I do not ask again. It is too hard on both of us.

An excerpt from an interview by a student in psychology at UCLA talking with a young adult who is retarded:

> What about your sisters and brothers? My brother had it much better than me . . . he always had friends. He always had a place to go . . . people wanted him . . . he was always doing more than I was, and interesting things . . . and I was . . . not having any friends . . . only my mother and father to help me.

Heavy stuff. . . My Leslie: "Kenny and Laurie go to happy schools; when I get to go to a happy school?" And, more recently: "Laurie run away from home; when it be my turn?"

Now, to put all this in some perspective, and, I hope, absolve the parents in the audience of guilt feelings they don't need, let me share my oldest child's casual and comforting response to my somewhat frantic long-distance request for guidance for today: "Mom, parents set up double standards for ALL kids." Maybe our families are not as unique as we suppose. (Maybe absence has mellowed her memory . . .)

Further, let me point out that crises of all sorts -- the death of a parent, divorce, serious illness -- create the need for pint-sized parenthood as well. Families are not utopias of harmony and growth. Sentimentality and romaticism ignore the realities. Albert T. Murphy comments: "A family is a powerful, emotional-packed setting charged through with love and anger, cruelty and tenderness, rejection and caring, frustration and joy, and not a little doubt. The presence of a handicapped child in a family can make us especially aware of the many expressions of emotion which characterize life."

I will -- almost -- end, appropriately, with a quote from a sibling. A 14 year old in an article on *Siblings of Autistic Children* [by Ruth Chirst Sullivan in the Journal of Autism and Development Disorders] has this thought for all of us:

> I used to think about how nice it would be if I had a normal brother, and our family was "normal" like all my friends' families. But after a while I realized that everyone thought that their families were weird . . .

And -- finally -- a sentiment I wish to share from another of my favorite parent authors. Clara claiborne Park, in *THE SEIGE*, speaks to what all we parents of handicapped children, concerned about all the *other* children we raise, need to recognize and hold on to:

> Elly has lived with us and the experience has been kept manageable. It's well to claim no more. One day, perhaps, my children will tell someone else of suffering I did not guess. But we have managed . . . And I am not really surprised. If I had any faith in all this business it was that we had good children, that they could help Elly, and help us, and help themselves through helping... I have never been sorry that our children had this trouble in the midst of all their good fortune. Our ancestors would have said that we all have our cross to bear. Our vocabulary is different, but the meaning is precious and should not be lost. The children have not grown up poorer for having Elly in their family. I think they feel this to some degree even now. Later they will know it.

NORMAL SIBLINGS OF RETARDED PERSONS

Meyer Schreiber

Abstract

Does being a normal sibling of a retarded brother or sister represent one of a variety of developmental sequences which represents a different route to effective social functioning or is being such a sibling a behavioral deviance which calls for professional intervention and corrective measures?

Five articles drawn from social work practice are examined along several dimensions such as purpose, problem formulation, theoretical approaches utilized, and strategies for social work intervention to test these assumptions about such siblings who are viewed as non-retarded intellectually average individuals.

From such beginning efforts there is evidence to support the view that such siblings reflect a variety of developmental sequences and social pathways.

1. Introduction

Although interest in the familial consequences of the presence of a child with a handicapping condition, such as mental retardation, is relatively recent, a review of published materials reflects consensus.[1] In essence, these professional views assert that these children may constitute an actual or potential threat to the family unit. At the same time there has been a significant amount of literature written by parents and relatives who maintain that the professional perspective is not congruent with their own.[2] It is important to note that a category such as mental retardation has a certain characteristic and significance. The mere labeling of a child has implications not only for the child's well being but for the family as well.

In specific terms, the demands of such children for care and management are said to disrupt family routines, restrict extra-familial contacts, sharpen or create new strains in family relationships and roles, and pose a threat to family morale. Despite this level of agreement, the evidence suggests that it is not altogether reliable and that it may be of limited application. It is necessary to avoid the tendency to assume that all family reactions and those of its members are the same. There are marked differences in the ways in which families react to stress and crisis during the various phases of the life cycle.

A great deal of this research, as well as practice efforts, has been focused upon the needs and concerns of the parents in dealing with this child who is different. All too little concern has been paid to significant others in the family, such as the normal sibling or siblings, who are non-retarded and intellectually average.

The key questions which develop from this concern about brothers and sisters are: is being a normal brother or sister of a retarded person a behavioral deviance requiring professional intervention or corrective measures; or are such siblings derailed from these social pathways in view of their family situation; or are there a variety of developmental sequences which represent different routes to social functioning and optimal living depending upon individual characteristics, family and environment?[3]

These basic questions have both theoretical and practical implications for social work with families with a child who is different, and all the dramatis personae in this social system.

2. The Literature of the World of The Sibling

While for a time in the post World War II years social scientists deplored the lack of studies dealing with sibling relations in the family structure, today there is a significant and emerging body of literature that suggest numerous findings that are replacing hunches with empirical data.[4] The importance of soliciting the participation and cooperation of the total family unit has gained increased social and clinical recognition and has replaced the previous emphasis of research and practice that almost exclusively focused upon the parent-child relationship.

Various studies about siblings have generated findings that indicate:[5]

1. sibling interaction usually takes place in conjection with the parent-child interaction; modifying, supplementing and occasionally replacing it.

2. sibling interaction is one of the basic ways in which personality is shaped and culture is passed on.

3. patterns of reaction and motivation are established.

4. philosophies of life are begun.

5. in many ways, interactions in the wider world are reflections of or outgrowths of the behavior patterns and interpretations that children learn in the home-based world of sibling interaction.

These findings posit that the products of sibling interaction include a sustantial impact on self-image including locus of control and gender identity, orientation to family of procreation and development and enhancement of skills and competencies in cognition, affect and social realms.[6]

Indicative of this growing body of literature is the nature of adult sibling life. One study suggests that 'sibling solidarity' is particularly prominent among people in the final stages of the life cycle, since at this time sibling bonds appeared partially to replace ties wth adult children.[7]

Today's frequent remarriages and divorces, another study suggests, may create future families in which the adult siblings have stronger ties to each other than to the parents and step-parents.[8]

While this growing literature may be found regarding families with 'normal' children, that for families with children which includes one who is different, such as a retarded child or one with a different developmental disability, is quite limited. There have been no significant or major studies in this area during recent years.[9]

The pioneer work in the area of families with a retarded sibling was accomplished by Bernard Farber, a sociologist.[10] In one study he reported that normal girls who interacted frequently with retarded siblings were more often rated by their mothers as possessing neurotic traits than did other girls who did not have as frequent contact with the retarded sibling.[11] In another study, he examined the "life goals" of boys and girls from ten to sixteen years of age.[12] He found that girls and boys who interacted frequently with such handicapped siblings showed less interest in goals related to success than in personal relations. His inquiry concluded with the suggestion that continued interaction with retarded siblings may come to be considered as a duty to the normal child. In the performance of this duty the normal siblings internalized welfare norms and turned their life careers toward the improvement of mankind or at least toward the achievement of goals which required the most dedication and sacrifice. Those individuals with a low level of interaction expressed more interest in socio-emotional goals like having lots of friends and getting along well with them.

Finally, he investigated the effects of the retarded child on affective communication between the parents and the children of normal intelligence in the family especially as such communication effects the socialization of normal siblings.[13] He regarded communication as the presence of the same definition of the situation in both the person who originated the definition and a second person who defines the situation through interaction with the origniator or his agent. From the perspective of social control and socialization, communication among family members is important insofar as it indicates instructions from one family member to another to continue or change patterns of activity. Farber's work suggested familial organization reflected in part the strategies they used to achieve their goals.

Such studies, and others, have tended to focus upon families with a severely retarded child. Practically all of these studies are about twenty years old and have not been replicated or extended since then in any major way.

Other studies of families with a child who is different with normal siblings have dealt with blind children and emotionally distrubed children. Generally the sample in such studies was extremely small, limited to two or three children and there was no significant trend to patterns emerging that yields anything more than what other studies have indicated.[14]

Studies dealing with different developmental disabilities, with various levels of disability in a sibling, different family statuses in socio-economic, racial and ethnic realms and varying child rearing patterns and approaches are not available at this point and are needed to broaden and deepen understanding of family and sibling processes of interaction.

3. Siblings in The Literature of Social Work

As a profession that still 'borrows' considerable of its knowledge base from the social and behavioral sciences while at the same time it is seeking to generate its own knowledge and theory, social work in its literature seems to reflect much of the developments from such sources. From these scholarly vantage points the focus in general, until recently, has tended to be upon the parental dyad as the chief area of interest regarding the family. Social work seems to have replicated much of this thrust.

Consequently as the concern about the parental dyad broadened and moved generally of the family as a social system, and a structure, the consequences were felt in social work theory and practice.

A literature search indicates that there has been a slow steady increase in the number of published social work materials dealing with siblings in the family.[15]

In 1967 Helen Harris Perlman shared perspectives about 'sibling support' as a corrective for persistent notions about sibling rivalry.[16] Jan Pfouts in 1976 referred to the sibling relationship as a 'forgotten dimension.'[17] She described the strong, ambivalent bonds between siblings and reported on a study of the effects that social comparison exerted on brothers -- effects that helped to shape the individual's identity, adult roles and peer relations.

A short time later Ralph Ranieri and Theodore Pratt advanced the idea of 'sibling therapy' as a means of enhancing family therapy.[18] This concept was defined as an effort "to resolve conflicts among children in a family by working with them as a group, apart from their parents."[19]

A review of the literature of sibling interaction by Grace Tsukado reflected the beginning nature of the development of this area of study.[20] This 1979 article included a discussion of a few studies of sibling relationships in a family where one such child was considered to be functioning at a disturbed level.

4. Social Work Practice with Normal Siblings

A literature search yielded only five articles which satisfied the dual criteria for inclusion in this inquiry: they reflected social work practice with normal siblings of an individual identified as mentally retarded, and such professional activity was accomplished by a social worker with professional training.[21] Social work journals; specialized periodicals in mental retardation and related developmental disabilities; those dealing with family life; sociological, psychological, educational and dissertation abstracts and unpublished agency materials were surveyed from 1950 to the present.

In general these practice efforts were analyzed along the following dimensions: purpose, problem formulation, theoretical approach, setting, strategies for social work intervention, outcomes and implications for social work theory and practice.

O'Neill. A state helath department provided the auspices where an evaluation and counseling program was made available to children who were retarded and to their parents.[22] In this clinic setting normal children often accompanied their parents and brothers and sisters. These normal siblings frequently expressed a desire to know about what went on in the counseling sessions; they seemed interested in learning about the nature of their brother's or sister's conditions. At times the clinic provided individual social services, usually casework counseling, to normal sibling where the need was indicated and the intervention appropriate.

This article dealt with the concern of a twelve year old girl who had a severely retarded five year old brother who the parents brought in for an evaluation before making a decision about institutional placement.

The worker's purpose was to help the normal child whose retarded sibling was involved in the agency service and to focus upon the felt difficulties that flowed from the presence of such a handicapped sibling in the family.

The problem formulation derived from the observation that normal siblings may have developmental problems and concerns flowing from the presence of a retarded brother or sister in the home, and that the strain may be felt by the entire family.

The theoretical approach was a developmental one in that the individual was perceived to be dealing with stress that was normal and appropriate to the family situation, and that the underlying behavior of the normal sibling was not pathological in nature.

The setting was a local evaluation and counseling clinic for children with some characteristics of mental retardation and under the sponsorship of the state health department. Parents were provided services as well in this organizational arrangement.

Social work intervention was supportive casework counseling which extended over four sessions. The twelve year old had some concerns about the home situation that she did not wish to discuss with her parents. The parents eagerly accepted the offer of the caseworker to meet with the daughter, and she responded positively as well.

The outcomes of such social work activity were that the help provided enabled this girl to express and to deal with her feeling in a way which released some of her own anxiety and some of the tension in the entire family.

The implications for social work practice point to the preventive nature of work with a family by spotting possible difficulty in family members, such as a normal sibling, and then providing short term supportive counseling to enhance problem solving skills. The recognition of, and focus upon, strengths within individuals living with and affected by individuals with a handicapping condition was an important professional gain. The value of providing support at an important time in a child's development was affirmed.

San Martino. As individuals and as a group, siblings of retarded individuals are perceived as a population-at-risk by a social worker practicing in association with a psychiatrist at a mental health clinic.[23] While acknowledgement is made of many factors that may account for problems in functioning experienced by this varied group of siblings, the professional perspective advanced is that guilt is the major element that accounts for symptomatic behavior which is expressed in unhealthy ways.

The purpose is conceived as a preventive one in dealing with mental illness in children. The problem formulation developed is that as a consequence of being a sibling of a retarded person in the family constellation this individual becomes part of an at-risk population in psycho-social terms.

The setting of this practice is a mental health clinic located in a suburban locality outside of a large metropolitan area. Within this agency structure the theroretical orientation or approach is derived from the psychological theories of Melanie Klein who asserted that guilt is a major psychodynamic. Her formulations are viewed applicable to this group of individuals in such family situations.

The client systems discussed are four boys; five, six, eleven and twelve years of age. The strategies for social work intervention included dealing with fantasies and behavior used to guard against guilt and anxiety by utilization of casework counseling within the context of Klein's theories. It was an intensive psychotherapeutic approach that evolved about Klein's "process of reparation" to alleviate guilt and anxiety. There are no outcomes discussed in the paper.

The implications posed for social work practice focus upon the value derived from early intervention modalities to reach designated risk populations, such as normal siblings of retarded persons, particularly at an early stage in their development.

Adams. The perspective that the normal siblings' functioning symbolizes well-being that contributes to the overall psychological health of the entire family thus aiding the retarded brother or sister is advanced by a social worker in a hospital clinic in an urban area.[24]

The stated purpose is to gear an evaluation and treatment program for retarded children to include significant others in family, such as normal brothers and sisters, who may need help in dealing with developmental tasks.

The problem formulation is that the normal sibling with a retarded brother or sister can face developmental tasks without major difficulties in growing up and in socialization although such individuals may encounter some problems that will require special understanding and insights.

Thus the theoretical approach or orientation is developmental in focus; the view is advanced that having a brother or sister who is different is a phenomenon that can be mediated and dealt with in the family context.

A large voluntary hospital located in a metropolitan area and providing a clinic service for retarded children and their families is the setting of this practice effort. The clinic provided evaluation and some treatment services for the children involved, and their parents. Often normal siblings were seen by the social work staff. An eleven year old normal sister is the client system dealt with here. A number of short descriptions of a variety of other siblings were provided. The strategies of social work intervention are education and supportive casework counseling. The outcomes are the enhanced capacity to utilize strengths by the normal sibling in dealing with the brother or sister who is retarded, as well as with others in the family.

Implications for social work practice are that the ways in which social workers view family members of individuals to whom they are providing services is important in extending the preventive aspects of work with families. The worker's focus upon the healthy components of a normal sibling's functioning and the strengths within that individual reflects an approach that contributes to the development of the person involved.

Murphy et al. Out of a concern that their services be family-centered, a group of social workers in a developmental clinic utilized group approaches to involve normal siblings of the retarded children in their practice.[25] The problem formulation was that the difficulties that parents of Down's Syndrome children experienced in dealing with such children often obscured their ability to understand how the other children are affected by this individual and family experience.

The theoretical approach or orientation was a combination of an educational program with a developmentally focused one. An educational thrust emphasized the provision of basic information regarding the biopsychosocial aspects of Down's Syndrome and the understanding that flowed from the use of such knowledge together with an examiniation of what growing up and socialization involved within the reality context of life with a brother or sister with such an assessment.

The setting was a developmental clinic for retarded children in a large metropolitan area and provided a range of services centered around evaluation and treatment for the child involved, and often the parents. The clinic was part of a hospital complex.

Social work intervention involved utilzation of group methods to set up small groups of normal siblings according to developmental levels. These groups were divided by age: 5-8, 9-12 and 13-19 years old. The beginnings were marked by an opportunity for all siblings to see the total group of brothers and sisters together as a means of sorting out similarities and differences with that of their own brother and sister.

The outcomes seemed to be increased understanding leading to the ability to deal with their feelings and concerns, and the ability to better manage the relationship with their own brother and sister.

Implications for social work practice seem to suggest that a family-centered approach is crucial in dealing with a child with a handicapping condition, and that such a line of professional activity has many preventive aspects for the normal sibling affected.

Schreiber & Feeley. A group of adolescent siblings were brought together by the social work staff of a parents' association for retarded children as a means of extending services to families.[26]

The purpose was to develop a demonstration program to assist the normal sibling to identify the nature of his/her reactions to having a brother or sister who was retarded and to help the individual clarify his or her strategies for understanding and dealing with siblings, parents and peers. The group defined its own purpose as being to help the members deal with their concerns about their retarded sibling, and the family.

As a result, the problem formulation was the need for the normal sibling -- within the context of a group experience -- to examine, clarify and understand more clearly a dynamic aspect of his or her life situation; the role as a brother or sister and as a family member and as a friend.

The theoretical approach or orientation can be identified as a developmental one which viewed the sibling experience as similar and different from that of a family with no member with a handicapping condition, and which involved working upon the developmental tasks involved.

There were ten adolescents in the group who ranged in age from 11 to 17 years. The group was equally divided between males and females, with the males being one to two years younger.

The setting for this experience was a large multi-service agency serving retarded persons and their families and under the direction of a board made up mostly of parents of such individuals. The agency was located in a large metropolitan area. The social work intervention strategy utilized the group method. Among the outcomes noted were that the support provided enabled the members to verbalize their feelings about their families and friends and especially their retarded sibling and to devise a series of strategies to deal with such concerns. As part of their group activity, the members developed a pamphlet titled "It's Tough To Have a Retarded Brother or Sister . . . But Here's What You Can Do About It."[27]

The implications for social work practice are that there seems to be a sizeable group of normal adolescents who desire a group experience where they can express their feelings in an open atmosphere and work out coping strategies as part of a preventive service. The use of the educational component included in this service underlines the contribution social work can make in dealing with populations with anxiety and stress flowing from needs for developmental task fulfillment rather than deep rooted pathology.

5. Summary Analysis of The Practice Efforts

Viewed individually, the practice efforts reflected a variety of approaches focusing upon the agency's and the worker's perceptions and definitions of the needs of the normal siblings of retarded individuals, and of their families. Viewed collectively, these practice efforts revealed many common understandings and some differences that contributed additional perspectives about the normal sibling and his or her needs.

Purpose. In all the five articles the purposes centered about helping the normal sibling deal with an assumed or felt difficulty arising out of the presence of a retarded sibling in the family. The institutional setting within which such services were provided set forth a framework of purpose. Thus help was extended in keeping with the agencies' direct service commitments and with their sanctions in the communities to meet and deal with selected human needs. In the Schreiber and Feeley article an additional dimension was added to the central purpose; that of developing a demonstration project to test the feasibility of group services to such adolescents.

It seemed that there was a clarity of purpose in regard to who was to be served, the agencies started with a dual emphasis of service to the retarded child and his or her parents and extended their horizons to encompass significant others in the family, such as the normal siblings, and thus generated a family approach.

There are references in some of the articles to the involvement of the normal sibling in understanding and accepting the agency's and the worker's purposes while articulating his or her own. In the O'Neill article the twelve year old sister wanted to know what was happening to her younger brother before he was to be institutionalized, and she desired an opportunity to deal with her own concerns which included both her brother and her parents. The Schreiber and Feeley article indicated the process of group formation which included full consideration by the group of its purpose which they defined as helping the members to deal with their concerns about their retarded siblings, and their families.

These papers basically emphasized or tended to view stress of such individuals involved from a developmental perspective that directed attention not only towards treatment approaches but also towards possibilities for prevention of difficulties before they arose. While there was a mix of individual and group approaches utilized in such provision of services, each was clearly focused on adaptive and developmental tasks of part of the central purposes.

Problem Formulation. With service and demonstration as a clear direction for work with the normal sibling, the problem formulation in all of the articles stressed the psychosocial impact of the retarded sibling upon the normal brother or sister and the entire family as well. These materials tended to view family dynamics as interpersonal relationships that could be changed and affected by the growth of any of the individuals in the social system, structure or process.

Developmental and adaptive tasks were viewed as crucial in dealing with the presence of a person who was 'different' in four of the articles. In the fifth one, San Martino asserted that guilt is a key psychological component that is present when one sibling is healthy and another is not, and has a lifelong chronic condition such as mental retardation. To deal with such deep feelings generated by the guilt, intensive psychotherapeutic measures would be needed to help that individual deal with his or her plight as a family member. The very use of the concept population-at-risk by San Martino to denote the normal sibling lends a dimension to problem formulation which seems rather total, and does not individualize or take into account where the normal individual and the family are in terms of family processes.

The Setting. Three programs were located in a medical or health setting; one was in a mental health clinic and the fifth was under the auspices of a parents' association for retarded children. One medical program was public in nature while the others were voluntary and non-profit enterprises. All agencies were located in metropolitan areas and accessible to the concentration of families in the heavily populated regions around them.

Historically, as the progress in serving families with a retarded member is viewed, the medical emphasis and the utilization of medical resources for early identification, diagnosis and treatment predominated. The utilzation of mental health facilities in the community came later as community mental health centers developed. The involvement of parents' associations reflected a long standing basic concern about the direct provision of services.

The dynamics of the settings emphasized that these were 'host' agencies in which social work was ancillary to the other services provided, particularly health and mental health. The parents' association may also be viewed as a 'host agency in view of its multi-purpose program orientation.

Professional affiliation strongly influences the professional's ideological position. The medical clinics reflected a growth orientation while the mental health clinic stressed a treatment approach, and the parents' association was concerned with reducing stress and anxiety by the provision of direct services.

The Normal Sibling. Numerically the normal siblings involved in the programs discussed in these papers was limited to selected individuals nd two groups. It was not a large sample as the articles dealth with professional practice and examined the complexities of working with selected individuals and groups and the discussion focused upon the dynamics involved.

Three of the articles dealt with individuals; one child, three children and five children respectively. Another article referred to work with several groups of children and young adolescents and the final article looked at work with a group of adolescents.

Young adults and adults were not served as most of the services described were limited to children and youth; this was particularly clear for the medical and health programs as the emphasis there was service in a pediatric program.

The socio-economic background of the children and youth and their families is not made fully explicit but there is some slight evidence that indicated that primarily middle class families were served.

It is interesting to note the emphasis upon service to children and youth as it is so prevalent in programs dealing with developmentally disabled individuals. One possible explanation may be the emphasis upon prevention, and consequently intervention at a young age is viewed as one means of reaching individuals at a developmental level which will impact upon their growth and development.

Theoretical Approaches. Most of the articles did not make their theoretical approaches or orientations explicit. O'Neill and Adams utilized some forms of psychotherapeutic formulations which were not specified.

The two group approaches were different. Schreiber and Feeley used the Schwartz "mediating or interactionist model" while Murphy seemed to have an educational focus primarily and did not make clear if there were any theoretical underpinnings utilized.

San Martino was the only practitioner in the five articles to specify a distinct theroretical position. She referred to the work of Melanie Klein, an English psychoanalyst, and utilized some basic concepts from Klein's work such as guilt and reparation.

The theoretical constructs used primarly focused upon some change in the normal sibling either through one-to-one work with the individual or through work with the individual's experience as a member of a group. Within such focus upon individual change there were some conceptual differences in these contemporary approaches to work with the normal siblings. Adams and O'Neill indicated that short term supportive casework counseling for the normal sibling would facilitate improved family functioning for all its members. San Martino indicated that work upon the intrapsychic processes of the normal sibling was an intensive process requiring considerable time. In a way Adams and O'Neill suggest a social systems perspective where improvement in one part leads to overall enrichment of the total system.

In the group methods utilized, Schreiber and Feeley dealt with helping the normal sibling mediate with his or her peer group, school environment and family. Murphy stressed the acquisition of information and knowledge.

Given similar concerns, professionals with different ideologies and theoretical positions operate differently. They emphasize different elements of the possible ways of perceiving the individual and his or her situation. Such ideology makes for a difference in the approach to treatment and prevention.

Strategies for Social Work Intervention. The five articles dealt with two approaches to social work intervention which encompassed various worker roles reflected in these materials.

Murphy's work with groups of various developmental levels could be viewed as an educational strategy which has as its objective helping the individuals and the groups to acquire information, knowledge and skills.[28] The activities included in this strategy are giving information, teaching skills, providing feedback, and demonstrating behavior. Schreiber and Feeley in their use of the group purpose to encourage the group to share their experiences with others utilized an educational strategy. The culmination of this process in a pamphlet written by the group, "Its Tough to Have a Retarded Brother or Sister . . . But Here's What You Can Do About It," illustrates this kind of intervention.

The other four articles emphasized the strategy of facilitation which seeks (1) to strengthen the individual's and group's capacities to mobilized internal resouces as well as to secure external ones, (2) to strengthen the integration of social systems such as the family and (3) attempts to create and build new social systems.[29] A variety of roles are used in this strategy and include helper, enabler and mediator. Worker activities include eliciting of informaton and opinions, facilitating expression of feelings, interpreting behavior, discussing alternative courses of action, clarifying situations and providing encouragement and reassurance. This strategy was clear in the Adam's article as she provided short term supportive counseling and similarly in O'Neill's presentation. San Martino in her intensive work with the siblings focused upon expression of feelings and interpreting behavior. Schreiber and Feeley used the group process to help its members express their feelings, clarify their situations, and discuss alternative courses of action.

Professional skill reflected in these articles was rooted in a social work knowledge base which was extended to another kind of individual in need of service.

6. The Central Issue: Professional Perceptions of the Normal Sibling

These five articles represent a beginning approach to the question posed at the outset: Is being a normal sibling of a retarded person a behavioral deviance requiring professional intervention and involving corrective measure or are there a variety of developmental sequences which represent different routes to social functioning and optimal living?

While each article was addressed to observations concerning direct services to such siblings and thus reflected advances in social work practice, yet each practitioner added a piece in putting together the central issue or question.

O'Neill, in her work with the twelve year old sister, was able to deal with this sibling's concerns about her brother and her family. This young girl's struggle was accepted by O'Neill as a genuine and positive expression of her family membership and the affectual ties it generated. It is the only article in which institutionalization of a brother or sister was mentioned as a key concern in the situation. O'Neill in her short term supportive counseling underscores the sibling's situation as being one of a variety of developmental sequences reflecting strength on her part.

In her article San Martino advanced the view that a normal sibling is part of a population-at-risk until the phenomenon of guilt is resolved through a process of reparation which is to be facilitated by intensive, extended psychotherapeutic intervention. This assumption placed the normal sibling in the position of being a person with a behavioral deviance and in need of professional help to make possible 'correction' for such disturbed intrapsychic processes.

The Adams' acticle stressed the normality of the sibling's reactions and concerns about the retarded brother or sister. She saw stress as evolving from family processes, and believed that short term help would facilitate increased understandings and insights. With such improved functioning, the normal sibling would contribute to their overall family's working as a unit. This social system perspective and developmental approach, Adam stated, reflected many common threads found in most families. Consequently, Adams' view was that for most normal siblings such a position in the family may represent another pathway and route to social functioning.

In the group approaches utilized by Murphy and her associates with siblings of Down's Syndrome children, the themes for work in the group seemed to be the tasks involved in growing up and meeting such developmental and adaptive expectations at various phases of the life cycle, including in childhood and adolescence. One such key task was how to live with a brother or sister who is 'different' and whose difference is visible for all to see. Murphy's emphasis seemed to be upon using the healthy components of the sibling's capacities to meet and to deal with such tasks. These group approaches seemed to support the view that for these normal siblings such activity represented a part of a developmental sequence which lead to enhanced social functioning.

The final article by Schreiber and Feeley saw the need to assist the normal sibling in rearranging and using what he or she already knew in dealing with developmental tasks. Consequently the sibling in this group developed strategies for understanding more about the retarded brother or sister, as well as the parents, and acting upon such newly developed knowledge. Thus Schreiber and Feeley emphasized such interaction within the family as part of the healthy give and take of family life. Such adaptive behavior was then perceived as another route and as part of a developmental sequence leading to strenghtened social functioning.

The limited experiences described in these practice efforts seem to suggest two beginning observations:

1. the view that the normal sibling, as a result of having a retarded brother or sister, has difficulties in dealing with adaptive and developmental tasks and is thus in need of some professional intervention leading to 'corrective' action is a limited one as it supported by only one of the five articles.

2. the assumption that the normal sibling with a retarded brother or sister is in a family situation that may represent one of many developmental sequences which represent different pathways to social functioning, is supported by four of the five articles.

The differences in these two orientations may be derived from how the practitioner views such stress and family living. The first approach would be inclined to view the sibling's plight as having internalized considerable feelings and thoughts, such as guilt, in intrapsychic and social processes and that this state of affairs needs to be mediated by professional help which makes available intensive activity leading to change, or correction, in that individual's behaviors.

The second approach sees transitional crises as predictable and necessary in response to the changing needs of the family members and to the pressures exerted by external systems such as peers.

The tentative and beginning nature of these observations suggests that their major value may lie in the questions that they raise for further study and the directions they point to for additional refinement and activity.

7. Conclusions

The purpose of this article was to draw the attention of social work practitioners and researchers to the subject of sibling interaction and family contexts, a neglected area of social work activity. This article has been concerned primarily with a presentation of practice efforts related to a research question, rather than an analysis of practice per se.

The practice efforts described in the five articles dealt with social work's contributions to the overall service delivery of a 'host' agency where the basic purpose dealt with the enchancement of mental health or health or improved family functioning. In these specialized settings the need to understand and to deal with both the basics and special needs of the individual and the family has tended to enhance practice and strengthen service delivery. This demand for the worker to be located in the two worlds of the normal and the 'different' has contributed considerably to social work knowledge and skill. Consequently, reaching out to serve normal siblings of retarded persons reflects an orientation that provides a tested approach which may be utilized in social work and 'host' settings, such as child welfare and family service, rehabilitation services, and work with elderly persons.

The theme advanced in these articles is the need for the social work practitioner and researcher to be sensitive to the entire sibling membership in the family.[30] The well being of all family members, including brothers and sisters and the key supportive roles that they play is crucial to the desired outcomes in work with the individual, whether he or she is 'different' or not, and the family.

While the articles reflected a variety of theoretical concepts such as general systems theory, developmental approaches, and various psychotherapeutic formulations, there seems to be a fertile field and opportunity for introducing and testing other approaches including those of Erikson and Piaget. The encouraging nature of the practice efforts discussed suggests some other areas for further inquiry as well.

The greatest needs seems to be for a longitudinal study that brings with it a more adequate understanding of the individual and social processes during childhood, adolescence, and adulthood that focuses upon sibling and family interactions. Such studies, both for the families with a sibling who is 'different' and those where no such handicapping condition exists, may be helpful in drawing attention to the many kinds of interactions within the family, the various and many developmental sequences and points in the life cycle where intervention is and is not appropriate. A number of variables would need to be included such as socio-economic status, race and ethnicity, family life styles and child rearing patterns and different kinds of handicapping and stress producing conditions. Further questions would need to include whether there is one sibling or many siblings, or large age differentials between siblings and the kinds of affectual coalitions that siblings and other family members build.

In summary, the question for such practice and research efforts would be: What are the different developmental pathways and sequences which may be normal for different kinds of siblings in different environments?

NOTES

1. An excellent review of these and related findings may be found in Jacobsen, R. Brooke and Humphry, Ruther A. "Families in Crisis: Research and Theory in Child Mental Retardation" *Social Casework 60* (December 1979): 597-601 and in Wolfensberger, Wolf and Kurtz, Richard A., eds., Management of the Family of the Mentally Retarded, (Chicago: Follett Publ. Co., 1969).

2. See Featherstone, Helen, *A Difference in the Family: Life With a Disabled Child*, (New York: Basic Books, 1980) and recent issues of the Exceptional Parent. Other materials written by parents are in Turnball, A.P. and H.R., eds. *Parents Speak Out: Views From the Other Side of the Two Way Mirror*, (Columbus, Ohio: Charles E. Merrill Co., 1978).

3. Chess, Stella, "Blind Alley" *The Sciences* 18 (April 1978): 25.

4. Irish, Donald P., "Sibling Interaction: A Neglected Aspect in Family Life Research" in Sussman, Marvin B., ed., *Sourcebook in Marriage and the Family*, 3rd ed., (Boston: Houghton, Mifflin & Co., 1968), pp. 293-301; Jacobsen and Humphry, "Families in Crisis: Research and Theory in Child Mental Retardation."

5. Smart, Laura A. and Mollie, *Families Developing Relationships*, 2nd ed., (New York: The Macmillan Co., 1980), p. 374.

6. Ibid, p. 375.

7. Cumming, Elaine and Schneider, David M., "Sibling Solidarity: A Property of American Kinship" American Anthropologist 63 (June 1961): 498-507; Allan, Graham, "Sibling Solidartiy" *Jl of Marriage and the Family* 39 (February 1977): 177-184.

8. "Siblings: Studies Find Rivalry, Dependency Revived in Adulthood, *The New York Times*, October 28, 1980, Science Section, p. Cl.

9. This observation is based upon a literature search utilizing the various abstracts available in the social and behavioral sciences.

10. Farber, Bernard, "Family Organization and Crisis: Maintenance of Integration in Families With a Severely Retarded Child" *Monographs of the Society for Research in Child Development* 25 (1960) No. 1.

11. Ibid.

12. Farber, Bernard and Jenne, William C., "Interaction With Retarded Siblings and the Life Goals of Children" Marriage and Family Living 25 (February 1963): 96-98.

13. Farber, Bernard "Social Context, Kinship Mapping and Family Norms" Marriage and Family Living 39 (April 1977): 222-240.

14. This observation is made from a careful study of the limited literature available from 1952 through 1982.

15. From a search of Abstracts in Social Work through the 1982 issues.

16. Perlman, Helen Harris "A Note on Sibling" Amer. Jl. Orthopsychiatry 37 (January 1967): 148-149.

17. Pfouts, Jane H. "The Sibling Relationship: A Forgotten Dimension" Social Work 20 (May 1976): 200-204.

18. Ranieri, Ralph F. and Pratt, Theodore "Sibling Therapy" Social Work 23 (September 1978): 418-419.

19. Ibid.

20. Tsukado, Grace K. "Sibling Interaction: A Review of the Literature" Smith College Studies in Social Work 49 (June 1979): 229-247.

21. A review made of the abstracts in the social and behavioral sciences from 1950 through 1982.

22. O'Neill, Jane "Siblings of the Retarded: Individual Counseling" Children 12 (November-December 1965): 226-229.

23. San Martino, Mary and Newman, Morton B. "Siblings of Retarded Children: A Population At Risk" Child Psychiarty and Human Development 4 (Spring 1974): 168-177.

24. Adams, Margaret E. "Siblings of the Retarded: Their Probems and Their Treatment" Child Welfare 46 (June 1967): 310-316.

25. Murphy, Ann et al "Meeting With Brothers and Sisters of Children With Down's Syndrome Children Today 5 (March-April 1976): 20-23.

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27. Available from the New York City Association for the Help of Retarded Children, 200 Park Avenue South, New York, NY 10003.

28. Pincus, Allen and Minahan, Anne, Social Work Practice: Model and Methods, Itasca: F.E. Peacock Co., 1973), p. 113.

29. Ibid.

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SIBLINGS' FEELINGS: A NEED FOR EXPRESSION

by

Marilyn S. Neel

> Children need freedom to express their feelings, both positive and negative. Sharing positive feelings - joy, pleasure, contentment - enriches the quality of family life. Learning to express the negative emotions - anger, hatred, jealousy - in appropriate ways is just as important. These feelings seem so strong that people often like to push them aside, in themselves or their children. But feelings are real, and part of being human. Getting them out in the open furthers the individual's mental health and the family's ability to communicate well.[1]

The above quote describes all children's need for expressing feelings. Indeed, this is no less important for a family of a handicapped child. One of the forgotten family members who may have a great many feelings; and needs to have permission to express them is the siblings of handicapped children. Much has been written about parents' feelings; i.e., the mourning the loss of the perfect, desired for child and how a family deals emotionally with that loss while struggling with the demands of parenting a handicapped child while maintaining some resemblance to a normal family life. In spite of the literature on a family's emotional adjustment, information about siblings' emotional adjustment and work that is being done with them is not as readily available. Traditionally, treatment has focused on the child i.e.: physical, occupational and speech therapy and then the family which usually involves Mom first and then Dad. Work with the parents usually focuses on helping them with the day-to-day care of their child and showing them how to help their child, so, in fact, they become their child's best teacher. At the same time, the parents may be struggling with their own feelings. Some are able to work this out on their own while others may need some professional help. Somewhere in all of this, the siblings may get lost.

The purpose of this paper is to explore the needs of siblings of multi-handicapped cerebral palsied children who are living at home and what implications this has for intervention with the siblings. This exploration of siblings' needs will be done by a combination of review of the literature on siblings of handicapped children, siblings and children's emotional needs in the latency - adolescent period and by the author's personal experience with siblings of handicapped children in a group setting. This exploration of siblings' needs will have a strong emphasis on feelings and the implications for working with them will be within a transactional analysis and systems theory framework.

This author has worked for eight years with families of cerebral palsied children and for the last two years with siblings of some of these families. This has been done directly and indirectly by supervising social work graduate students who have led the groups.

In a review of the literature of siblings of the handicapped, it appears that an interest in such has really only occured within the last fifteen years.[2] One of the early studies entitled Brothers ans Sisters of Retarded Children: An Exploratory Study was done by Frances Kaplan Grossman in 1972. Since then articles have been more frequent in such publications as The Exceptional Parent and writings such as Robert Myers' Like Normal People. Recent books on families of the handicapped have begun to mention siblings and their role in the family. Helen Featherstone in A Difference In The Family gives a nice summary of sibling adjustments, although it tends to dwell more on the negatives than the positives. Recently, since 1981, the Sibling Network Newsletter has been attempting to coordinate what is available in terms of literature and what is being done across the country. It should be noted that the group with which this author has direct contact was featured in the May, 1982 issue of the Newsletter. From the amount of interest from across the country, there appears to be a growing interest in working with siblings.

Although there seems to be more information available, most of what this author found available in doing a literature search was from an older sibling's viewpoint who is looking in retrospect at growing up with a sibling. I will be combining these thoughts with what I have found to be actual experiences of siblings ages 9 - 16 while growing up with a younger handicapped sibling living at home.

I will now describe the groups I have been working with and their experiences with a handicapped brother or sister. These experiences will then be compared to what has been described in the literature and finally, I will discuss implications for the future.

Sibling Group began over two years ago upon the suggestion of the older siblings in one of the core families of the group and also because of the interest this author had in the effects of cerebral palsy on the entire family system. The group was structured much like Frances Grossman structured her discussion group with adolescents who had a sibling at the regional residential center.[3] However, this was unknown to the group leader at the time of formation. The first group consisted of five siblings ages 12 - 15 from two families. A second group of younger children ages 9 - 11 was begun the following fall.

The first group met initailly for eight weeks for 1 1/2 hours each session. Later (in the fall) this changed to every other week. The second group met for an hour since the children were younger. Both groups have been combined for special events such as a television taping on the subject, decorating a public relations window on cerebral palsy and for a Sibling Day held this past summer which included more siblings not involved before. Members for the group were selected from families at a Cerebral Palsy Treatment Center who indicated interest in such. All children in the pre-selected age bracket were contacted by talking with the parents who then talked with the brother or sister. The members happened to live within close proximity to one another which is primarily in the suburbs of a metropolitan area. All siblings were older than the handicapped sibling who lived at home.

The groups have been very successful as evidenced by the siblings' continued interest in participating. Attendance has been regular with all the members of each group usually present. The interest and excitement level remains high at each meeting, as evidenced by their wanting to meet longer and more often. The problems Frances Grosslman described in her initial work with a group of siblings were not encountered.[4] The reason for a high success rate may be attributed to a variety of reasons. These are 1) All the parents were extremely interested in their children participating. 2) The parents did not push their children into coming, but rather supported them. 3) The parents provided transportation and in some cases a place to meet. 4) All the parents had participated in some type of parent support group at the United Cerebral Palsy center sponsoring this project and were aware of the benefits of meeting with people in the same situation. 5) The parents were concerned about the effects of their cerebral palsied son or daughter on the other children.

At the present time the older (initial) group consists of five teenagers ages 12 - 15. There are two boys and three girls who are in high school. Their brother or sister's handicaps are varied and range from severe to mild cerebral palsy and from normal intelligence to moderate mental retardation.

The younger group consists of five children ages 9 - 11. Their brother or sister's handicaps cover the same range as in the older group.

The purpose of the sibling groups is to provide a support group in a safe environment where there is permission to feel and express all kinds of feelings, to learn how to handle these feelings, to learn how to ask for what they need emotionally in the group and then in the family, to learn more about cerebral palsy and handicaps in general and finally, to become comfortable with handicaps and as a result to teach others;

their peers included, about them and that it is okay to have a sibling with a disability.

Most of the siblings feel the group is a safe place to talk about how they feel about their brother or sister or a one member says, "to let off steam" and a place to learn more about their sibling's handicap. This is done in many ways from talking and sharing feelings to doing exercises and role plays to simulate having different handicaps and then talking about their feelings from such experiments. Included in this are learning appropriate healthy ways to deal with such emotions.

Naturally, negative and positive feelings have been expressed. I will separate these into the four basic feelings of sad, mad, glad, and scare. Some people may not have permission to express any of all of these feelings or may not be allowed to do so in their families. It is important within the group setting to give permission for expression and that the sibling does not necessarily need to have a reason for feeling that way.

> Your feelings are as real as your big toe. Do you need a reason to have a big toe? It's a part of you and they are real.[5]

The most prominent feeling is mad or anger usually disguised as resentment and jealousy. Pure anger, itself, is difficult to talk about and usually needs to be encouraged in a safe environment. There is a strong feeling that the handicapped sibling gets too much attention. Of course, the handicapped sibling usually requires a lot of attention because of his or her special needs such as medical appointments, exercises, school meetings and the extra time that is required for activities of daily living. Although trips to medical appointments, including therapy, are viewed as necessary by the parent, they may be viewed as fun by the other sibling. Not many parents would see this as fun - rather something that is necessary and that they do out of love. This is especially true if it includes a trip for lunch such as McDonald's. One Sibling Day participant was glad to spend the day at the center. She was envious that her sibling got to come to town each week. Resentment also comes from normal family activities which may not take place because of the time and energy that is involved in taking the handicapped sibling with them, i.e.: it may be too difficult to take the wheelchair or they cannot because they do not have a van with a lift or because of the handicapped sibling's behavior in a restaurant is "abnormal". Other normal family activities such as a "normal" family supper may be impossible because the handicapped sibling needs to be fed or eats as a small child would. Another cause for anger is that the sibling may equate money with love. Providing for a handicapped child is costly, especially when it comes to adaptive equipment such as electric wheelchairs and computerized communication devices. Although insurance and private/public donations may cover part of the cost, children do not take that into account and view the amount spent on the handicapped sibling as love; and because they have not received anything as expensive they feel they are not loved. One girl in the group felt glad to know her parents were going to buy her braces for her teeth since they had spent over $10,000 on her brother's electric wheelchair and communication system. Getting braces seemed to make her feel more loved and a part of the family. Featherstone discusses this same issue of anger and special attention in A Difference in The Family:

> Children feel angry: at parents, at the disabled child, at the wider world, at God or fate, perhaps all four. Some blame their mother or father for the disability itself (just as they blame for a newborn baby). A handicap creates unusual needs; many children envy their brother/sister this special attention. And older children may rage secretly about the sometimes colossal sums of money spent on diagnosis and therapy -- Resources that might otherwise finance family comforts and college tuition.[6]

The attention that the other siblings perceive their handicapped sibling to demand is also evident by a collage that one group member made of her sister. The word LOVE was in the center of the collage with all the pictures that described her sister around it. The sister went on to explain that this described the attention her handicapped sibling demanded from the family.

The second most expressed feeling is scare about their handicapped brother or sister as shown through their concern about them being teased when out in public or at school and what happens in the future, especially when Mom or Dad is or both are gone or are no longer able to take care of the handicapped sibling. There is also some scare over if they will have a handicapped child when they grow up. The scare is expressed mainly through embarassment and the protective reactions that the sibling expresses toward the handicapped sibling. The older sibling in the family, especially the girl, will turn this scare/concern into a protective/mothering attitude and will not want the handicapped sibling to take risks and get hurt. Sometimes the siblings are much more overprotective than the parents themselves! Helping them learn the principle of dignity of risk has been quite helpful. Another way the sibling may want to protect their handicapped sibling is from the cruel looks and words that are said by other children. The siblings hurt when someone at school makes fun of handicapped people and uses words such as retard or spastic. The sibling really hurts deeply when this happens and wonders how their brother or sister feels when this happens when their sibling is mainstreamed. This is one of the reasons they want to share with others their knowledge of handicaps and that having a handicapped person in your family is okay.

There is definite gladness and happiness expressed -- all of the siblings love their brother and sister and are excited over the things they may be learning. Their love is exhibited, too, by their wanting to teach people about cerebral palsy and other handicaps.

Sadness is also expressed in a variety of ways. The sibling is sometimes sad for themselves that they do not have a normal brother or sister and may feel sorry for themselves. They also may feel sorry for the handicapped sibling that they may not be able to do a lot of activities and have the same kind of life experiences that a normal sibling may have.

Another interesting reaction from the siblings is that they may be more realistic about their brother or sister than their parents. One group member recently said her Mom treated her two year brother like a baby and he was no longer a baby! We have also found that in families where there are only two siblings, the normal sibling may not have a frame of reference of sibling relationships, so many normal sibling interactions such as jealousy and rivalry may be viewed as abnormal and things that happen only as a result of the handicapped child.

Although heavy emotions are dealt with in Group, the siblings perceive Group as enjoyable. The group discussions are held in a fun way and the siblings do many fun activities together while dealing with these emotional issues.

Although I have simplified the siblings' feelings into the four basic feelings, what has been described are really not much different from those described by Featherstone (fear, anger, loneliness, guilt) and the embarassment as described by Grossman, by Robert Myers' story of his brother in Like Normal People, and by Gerri Zatlow in "A Sister's Lament" in Exceptional Parent.

From my ongoing experience with siblings of cerebral palsy brothers and sisters, I have found that like the parents, the siblings have many feelings, emotions and questions which they need to get out into the open. This is also evident in the writings of Featherstone[7] and in several articles in The Exceptional Parent. There seems to be a lack of communication if families whereby the parents have not explained to the sibling what is wrong with the handicapped child and why the family has decided what they have decided to do, i.e., school placement, homebound, residential, etc. Another difficulty arises when the parents are not sure of the diagnosis and therefore cannot explain to the other family members. This problem increases if there is no permission to ask questions within the family setting. I have found that Group, like with the parents, is one good way to talk about having a handicapped brother or sister. Group, of course, is not for everyone, and some siblings will need individual counseling. I have found Group to be excellent for the following reasons: it can provide a good peer support system at a time in a youngster's life when peer relatioships are very important; it is a safe place to express feelings or to learn to express them, a sibling may learn a lot by listening and not have to say much until he/she is ready to do so.

Working with the siblings in this format has made me aware of what siblings need regardless of whether they are in a group or not. They need to know they are important, worthwile and loved members of their families. They need to know it is okay to express positive and negative feelings; they need adult information about handicaps and future arrangements for their sibling; and finally, they need to learn how to ask for what they need emotionally. Working with the siblings also includes working with parents. The parents need adult information from professionals who at the same time can provide nurturing and stroking for the parents so they can provide this to the rest of the family. This is one of the reasons that I think it is vital for a family to remain in touch with a center that works with the handicapped. The family needs a larger support system that it can turn to for information and help as needed.

Are these needs of these teenagers any different from other teens and siblings? Not really -- all children and adults need positive strokes and affirmations for their being, for their capability, for their thinking and worthwhileness. The need for these affirmations are explained and described simply in Jean Illsey Clarke's Self-Esteem - A Family Affair.[9] Many studies on normal siblings' relationships reveal feelings of preferential treatment and favoritism, a lack of communication as leading to misconceptions, sibling rivalry and competition.[10,11] However, it appears these feelings are intensified in a family of a handicapped child, especially when there is not enough permission to talk about them. Since people have the opportunity to change, or in transactional analysis terms, to recycle,[12] it is hoped, through such group experiences with professional guidance, the siblings will learn new ways to handle their feelings both inside and outside of the family setting. Hopefully, their lives will be enriched through such experiences and will have lasting positive effects so that life with a handicapped sibling will be more positive and healthy.

FOOTNOTES

[1] Saf Lerman, Parent Awareness Positive Parenting for the Eighties (1980), p. 85.

[2] Frances K. Grossman, Brothers and Sisters of Retarded Children: An Exploratory Study (Syracuse, 1972), p. 24.

[3] Ibid., pp. 25-37.

[4] Ibid., pp. 26-37.

[5] Alvyn M. Freed, T.A. For Tots (Sacremento, 1973), p. 92.

[6] Helen Feathersone, A Difference in the Family (New York, 1980), p. 143.

[7] Ibid., pp. 150-151.

[8] "Siblings of Children with Disabilities", Exceptional Parent (December, 1979), p. C29-C32.

[9] Jean Islley Clarke, Self Esteem: A family Affair (Minneapolis, 1978), pp, 263-265.

[10] Arnstern, Helen S., Brothers and Sisters and Sisters and Brothers (New York, 1979).

[11] Neisser, Edith G., Brothers and Sisters (New York, 1951).

[12] Clarke, p. 272.

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GROUPS FOR NORMAL SIBLINGS OF DEVELOPMENTALLY HANDICAPPED CHILDREN

Thomas E. Mates

Elizabeth R. Willetts

Elain L. Goolsby

The purpose of this paper is to present a practical guide for those professionals interested in developing closed, short-term, sibling groups. First, the rationale for including siblings in service programs for the developmetally handicapped is described. Then, a model for establishing groups is presented focusing on basic group formation issues as they relate specifically to the sibling population.

The holistic view of the family as the identified client system is well-accepted by professionals working in the area of developmental handicaps. Despite this focus on the family, services provided to the normal siblings of handicapped children have been limited and inconsistent.

There are three cogent reasons for including siblings when planning services for families with handicapped children. First, the chronicity of the affected member's handicap influences family relationships. It affects daily household routines and neighborhood relationships and the emotional and physical health of individual members. Whether the family is strengthened or stressed by this unique situation is dependent upon how each family member copes with and adjusts to the stress, which in turn influences other family members.

The second reason for offering services to siblings is that they often become an integral part of the handicapped child's home management program. There are several documented cases where the sibling has been the primary trainer at home: (Cash and Evans, 1975; Miller & Miller, 1976; Weinrott, 1974). Siblings also contribute to their handicapped brother/sister's welfare in an indirect fashion by the support they offer their parents: (Bristol, 1979; DeMeyer, 1979).

The third reason for offering services to siblings is directly related to the first two. Namely, when one considers the unique stresses of living with a severely handicapped child, it is not surprising that many professionals feel these siblings are at risk for developing emotional, behavioral and academic problems. Farber (1963) reported that siblings were adversely effected by the handicapped child's dependency and by excessive child care responsibilities. Gath (1979) noted that excessive responsibilities undertaken by siblings contributed to behavior problems in school and at home. Although the negative effects noted above were corroborated in other studies, several authors have found siblings to demonstrate no negative effects (Grossman, 1972; Cleveland and Miller, 1977). The results of two studies in fact (Mates, 1982; Berger, 1981) suggested that the siblings of some autistic children demonstrated a higher self-concept than that considered average in the general population.

Naturally, a great number of family and individual variables that a researcher is unable to control inhibits his ability to relate the sibling's adjustment directly to his having a handicapped brother or sister. It is clear, however, that neither a family nor a sibling remains uneffected by living with a handicapped child. Although it seems that most siblings are not at risk for serious psychopathology, it is apparent that they have increased responsibilities, many difficult to answer questions, and parents that are continually dealing with signficant stressors and consequently have less time to spend with them and attend to them.

In response to these unique stressors and potential problems, several clinicians have organized support groups for siblings. The groups have provided siblings a supportive environment where they can ask difficult questions, express confusing and contradictory feelings, share successful strategies for coping with and teaching their handicapped brother/sister and establish friendships with peers sharing similar experiences.

Schreiber and Feeley (1969) described a group consisting of ten adolescent siblings. Issues addressed in this group included: a) how to tell friends about the handicapped child; b) how to deal with feelings of jealousy about the excessive attention the child receives; c) how to communicate with and ask questions of parents who are secretive; d) what is the nature of the handicapping conditions and e) what are the implications for future care of the handicapped child. Group members reported that the experience encouraged them to talk about their concerns and assured then that they were not alone. Kaplan and Fox (1968) conducted a similar group for adolescent siblings of retarded children. The issues they focused on included: a) disciplining the retarded child; b) dealing with feelings of embarrassment and anger towards friends and other people who laughed at the retarded child; c) talking with parents; and d) establishing identity separate from the retarded child. Feigon (1981) describes an ongoing sibling group in a hospital which follows the needs of the participants and usually focuses on four areas: a) family; b) intrapsychic feelings; c) interpersonal issues; and d) social needs. She reports that the siblings respond positively and that, although some parents were initially hesitant about the group, they invariably ended up supporting it. Everybody Is A Person: A Book for Brothers and Sisters of

Autistic Kids (1979) is a product of a sibling group, which captures the essence of the discussion carried on by the young participants. It describes autism in words children can understand, suggests ways of explaining the handicapped sibling's behavior to friends, and discusses positive and negative feelings children experience in response to living with an autistic child.

By reviewing the content of other sibling groups and listening closely to many siblings, the authors of this paper have identified three distinct areas to consider when forming a group: a) understanding the handicap; b) identifying and dealing with feelings and; c) learning problem-solving skills to help deal with stressful situations. The model presented in the following section incorporates these issues as possible organizing themes for a group.

A MODEL

The following review of group process considerations is offered in hopes that it will facilitate the formation of more groups for siblings of handicapped children. This model is presented as a guide, but successful groups with characteristics other than those proposed can be established with appropriate flexibility and imagination.

Group Process Issues

Programming: The primary concerns of siblings applicable to programming include: a) the need for education and knowledge about handicaps; b) the emotional response to the handicapped child and to the reaction of others to him/her; and c) learning specific ways for dealing with stressful situations. The number of sessions used to review each content area will depend upon the total number of planned sessions. For example, adolescents who are meeting for twelve sessions could use two sessions for orientation and goal setting, three sessions for each content area and one session for evaluation and wrap-up.

Using this model, the first sessions should focus on members meeting each other and establishing their identity independent of their handicapped brother/sister. This can be accomplished by "ice breaker" activities. Both the overall purpose and individual expectations for the group should be discussed. This in turn will lead to establishing specific group goals. Members should be encourged to generate individual goals as well. Finally, each member should describe his/her handicapped brother or sister, telling about his/her age, disability, school placement, strength, weakness, special interests, etc. It is important to have members identify their own strengths and weaknesses as well.

During the sessions focused on education about handicaps, issues addressed can include: kinds of handicaps, etiology, genetics, future implications and individual differences. The next module should focus on identifying feelings about having a handicapped brother or sister, feelings towards parents related to the handicap, and feelings about the reactions of friends and strangers. Both positive and negative feelings should be elicited and supported.

The final content module should address problem-solving strategies for appropriately handling stressful situations, using behavior management techniques, and being an effective advocate for the handicapped child.

Perhaps the area requiring the most ingenuity on the part of the group leader(s) is the generation of activities to facilitate the objectives for group sessions and to maximize the participation of individual members. It is essential that individual sessions be carefully planned by identifying specific objectives. The most critical factor in this selection of activities is that they be matched to the developmental level of group members. For example, most young adolescents are capable of talking about their feelings and doing role modelling in an open-ended fashion. Elementary age children on the other hand, respond better to more structure.

Activities that can be used by adolescents include: a) role play; b) brainstorming; c) working in groups of two or three on a specific issue; and d) joint efforts toward creating a project such as a book or video tape to be used by others. Younger group members require more experiential activities, such as games, art work, and cutting out pictures that represent their feelings.

Evaluation: Evaluation is an essential part of the group process and should be incorporated at the planning stage. In order to conduct a useful and valid evaluation, there has to be clearly specified goals. There are at least three parties who may have goals for such a group. The leader(s) have both group goals for individual members, each member has his or her own goals, and parents of the group members have some goals as well. Obvious group goals of attendance, participation and productivity can be evaluated by reviewing notes from each session. More specific group goals such as mastering problem-solving skills, identifying feelings, increasing self-concept and learning more about developmental disabilities can be evaluated with pre- and post- paper and pencil tests. Presently, there are no standardized tests that address these issues except self-concept scales which may not necessarily reflect the development resulting from such groups. Schafer and Edgerton (1979) have recently developed an instrument that asks parents to access the nature of interactions between handicapped children and their siblings. This has great potential for being a pre-post test for evaluating sibling groups. Finally, it may be necessary for leaders to develop their own questionnaires. The benefit, of course, is that these will directly reflect the group's focus.

Individual goals can best be evaluated by the person choosing them. It is necessary, however, to have members identify their individual goals and to share these with the leaders. Then during the last session or during ongoing sessions, the leaders can develop structure to enable group members to make a judgement about their attainment.

Parent goals may range from a simple desire of seeing their child involved with other siblings to unrealistic hopes such as improved school performance. It is suggested that the leader(s) maintain contact with parents and welcome their feedback, formally or informally. If one of the group members has demonstrated significant adjustment or emotional problems, suggestions can be provided to the parents for appropriate services.

Evaluation adds closure and identifies which elements of the group are effective and which need re-thinking. It also contributes useful information for other professionals establishing sibling groups.

Membership Characteristics

Recruitment: Recruitment of siblings is not an easy task. Even though the group has a "preventive" rather than "treatment" approach, many families of siblings do not connect their normal child's concerns or problems with having a developmentally handicapped child in the family. Unaware of the potential benefits their normal child may receive from participation in a group, parents must sometimes be "sold" on the idea of a group experience. Opposite this is the parent who becomes aware of the group and wants his/her child to participate, despite the fact he/she does not meet the critical attributes criteria of the group being formed. Such children can be considered when forming future groups and for alternative services as needed.

Potential referral sources include Associations for Retarded Citizens, developmental schools, public schools, mental health centers, and private physicians. Descriptions of the group's goals, purposes and membership attributes should be distributed to these service providers to insure appropriate referrals. Gaining their support and enthusiasm for the group will ensure a maximum number of candidates. Confidentiality regulations may prevent the referral source from releasing identifying information about potential group members. The referral source is then left with the responsibility of initially contacting families, acquainting them with the group, and obtaining permission for referrals. Upon receiving the names of potential group members, telephone calls to the parents are suggested to better acquaint them with the group, its goals, and to answer any questions they might have.

Home Visits: Having identified potential group members, thirty to forty-five minute home visits by the leader(s) are suggested. Home visits are best made when the entire family can be present: parents, the potential group member, the handicapped child, and other household members. Family dynamics can be observed, giving the leader(s) a better idea as to what the group member's daily experiences are like. These visits may also serve as a "screening" technique for inappropriate referrals.

Socio-economic Status, Race, Sex: Socio-economic status does not appear to be an important consideration in the formation of effective children's groups. Rose (1974) reports that some diversity in areas such as this can be tolerated and may be advantageous in children's groups where problems are related to social adjustment. A combination of different races and sexes may also prove helpful, but caution is advised where there is extreme imbalance. Individual personalities and the group leader(s)' skills determine whether or not such differences will interfere with group effectiveness.

Age: Homogeneity of developmental age range is considered critical. The developmental level will dictate the members' ability to understand and communicate feelings, their interest in the group, the length of individual sessions and activities they would be interested in. Adolescents have been found to be quite articulate about difficulties with their developmentally handicapped brother or sister. With support, these adolescent siblings can be mobilized to constructively handle this difficulty in groups (Adams, 1967). Latency age groups can also be successful as well, provided the developmental level is taken into consideration when planning and programming the group.

Emotional Status: Membership should exclude siblings who are exhibiting significant problems in their school or home adjustment. Siblings with severe emotional problems should be referred for treatment elsewhere. Normal stresses which relate to having a handicapped brother or sister are expected.

Research, clinical experience, and social psychological theory suggests using each member's behavioral characteristics to mix together a behaviorally heterogeneous group (Rose 1974). With this balance, group members who have higher levels of positive interactions with their siblings can serve as role models for those members experiencing difficulty in a particular area. These "role models" in turn receive the satisfaction of helping others with their problem-solving strategies, etc., thus allowing for rewards for all members.

Achievement of heterogeneity in group membership may also decrease the likelihood of having a group where nothing positive can be expressed about having a developmentally handicapped brother or sister.

Handicapped Child Characteristics

Degree or nature of the handicap: Unless there is access to programs serving a specific population, group leaders are likely to experience difficulty recruiting members if limited to siblings of children with specific disabilities, e.g. autism, Down Syndrome, etc. If this can be arranged, it would give members a greater sense of commonality in relation to the group's objectives. Where this is not possible, both the differences in handicaps and level or severity should be considered in programming for specific sessions.

Age: Homogeneity of this attribute is not felt to be critical although an argument can be made for requiring the brother or sister to be old enough for the developmental handicap to be recognizable.

Place of residence: Homogeneity of the group members in terms of whether the handicapped child is in the home or institutionalized is suggested. Problems may result if there is only one member whose handicapped brother or sister resides outside the home. This may lead to a lack of group acceptance of this particular member. The "outsider" may also be covertly blamed by others for the removal of the handicapped child from the home. Members whose handicapped brother or sister is in the home may be concerned about things such as how to tell their new friends about their sibling whereas members whose siblings are institutionalized may be concerned about how to answer questions as to the whereabouts of their brother or sister or their feelings regarding their absence.

General Considerations

Group Leader: Sibling group leadership can be a rewarding challenge for a variety of professionals interested in this population. Among those who may accept this challenge, are psychologists, guidance counselors, and social workers. Group leadership is an important determinate of any group's effectiveness and is not suggested for those untrained in group methods. A knowledge of developmental handicaps and family concerns is essential. Extra energy and enthusiasm are also seen as necessary characteristics of the sibling group leader.

While no literature has been found on the use of co-leaders for this kind of group, they have the advantage of having each other's ideas and suggestions in planning strategies of intervention and in processing at the conclusion of each session. Opposite sex co-leaders may benefit the group by providing both male and female members a same-sex adult from which they can model.

Group size: Considerations that enter into determining group size include the sibling group's objectives and the attributes of the members. Limiting the group to eight to ten members makes it small enough for intimacy of members while large enough to permit some members to be absent or drop out without negative consequences for the entire group. Last minute decisions of potential members not to join, transportation difficulties which prevent attendance, and other circumstances are likely to change the group size at the last minute. Therefore, it is suggested that ten to twelve potential members be initially selected to compensate for predictable attrition.

Setting: The location of the sibling group should be decided during the planning phase. Location should be as accessible as possible for all members (e.g. on public transportation route, centrally located, etc.) and safe in the event members arrive or leave the sessions alone. Schools, churches, and various social agencies are a few of the possible locations for the group. School classrooms are a possibility, but are not recommended. Members may associate the group sessions with school itself which may hinder the group's development. Use of large spaces or rooms (e.g. a cafeteria or gymnasium) is also discouraged in that they do not provide a feeling of intimacy for the group. The room should be private and comfortable, located away from distracting noises and possible interruptions. Doors should be kept closed to insure a sense of privacy, thus facilitating participation. A table should be available for working on projects and comfortable chairs for discussion periods. Informality will help foster a comfortable mood for the group's interactions.

The same building and room should be used for all the group sessions if at all possible. Members are thus able to set up a routine for transportation and there is little or no chance of their being dropped off at the wrong site or having to wander around the building looking for a new room. Setting an atmosphere conducive to achieving the group's goals and other signs of preplanning by the leaders (e.g. refreshments, etc.) convey to the members that the leaders are not only prepared for them, but also care.

Number of Sessions: How many times the group will meet is another important element to consider and should be determined prior to recruitment of members. This information enables the parents to make a more informed decision about their child's attendance. Goals are more likely to be accomplished if the duration of the group has been predetermined as opposed to being open-ended (Bertcher and Maple, 1977). This may also improve the sibling's desire and commitment to attend. It is recommended that sessions for closed, short-term groups be set somewhere between eight and twelve, with the actual number dependent on the age of group members and specified goals. Toward the scheduled end of the group, a decision can be made as to whether the group wants to have future sessions. In this event, the same planning process as described above should be repeated, including specific goals and a fixed number of sessions.

Time/Length of Session: Both the time and the day of the week the group meets should take into consideration the individual members and their family schedules so as to make attendance possible. A weekday afternoon schedule for the sibling group is recommended so that the family's evening or weekend time together is not interrupted. When possible, meeting times should also take into consideration regularly scheduled events and extra-curricular activities which potential group members may participate in, e.g. Tuesday afternoon basketball games, etc.

Sessions of up to ninety minutes may be appropriate for adolescent groups whereas somewhat shorter sessions may meet the needs of younger children. Sixty minutes should be the minimum length for sessions if a relationship is to develop and goals accomplished. Developmental level of members should thus be considered when determining session length.

Once a week, a common frequency of sessions for groups, is proposed. Longer interims require that time be spent re-establishing the relationship and reacquainting members with goals and purposes.

CONCLUDING STATEMENT

The value of supportive and preventive services to siblings of handicapped children has gained increasing recognition. Although research findings are inconclusive about the emotional status of these siblings, the reality of their situation confronts them with the necessity of adjusting to a unique challenge. One alternative to the provision of services to this population is the development of closed, short-term groups to provide an environment for education about handicaps, sharing feelings, peer support, and mutual problem-solving. It is hoped that the model described in this paper will facilitate development of such groups.

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MODIFICATION OF SIBLING INTERACTION IN FAMILIES WITH A MENTALLY RETARDED CHILD

JoEllen Hofmann Vespo

ABSTRACT

Mentally retarded children may engage in more disruptive behaviors than non-handicapped children, which affects the pattern of interaction within the family and may affect the later social development of the family members. This study was designed as a preliminary investigation of the nature of interactions among mentally retarded children and their siblings. It was found that the siblings may inadvertently reinforce disruptive behavior by attending to it or by counterattacking, but that also, they can learn how to modify their own behavior in relation to the mentally retarded child's behavior, which resulted in more positive interaction among the siblings. It is suggested that the family unit is a rich context in which to study the formation of early perceptions and patterns of interaction and how these influence later social development.

MODIFICATION OF SIBLING INTERACTION IN FAMILIES WITH A MENTALLY RETARDED CHILD

In recent years there has been increasing pressure for the deinstitutionalization of mentally retarded individuals, which has resulted in the majority of these individuals living either at home with their families or in community based group homes (Grossman, 1972; Scheerenberger, 1976). A major goal of deinstitutionalization is to provide the mentally retarded individual with as normal a life as possible (Grossman, 1972; Scheerenberger, 1976). It has been shown that in order to achieve the goal of successful intergration into the family and the community mentally retarded individuals must reach some level of competency in social skills and self-care behaviors (Love, 1973; Miller and Cantwell, 1976; Reiter and Levi, 1980; Stacy, Doleys, and Malcolm, 1979; Sutter, Mayeda, Call, Yanagi, and Yee, 1980).

Applications based on social learning theory have been used to improve a wide range of social behaviors in mentally retarded individuals (Barton, 1970; Barton, Guess, Garcia, and Baer, 1970; Foxx and Azrin, 1972; O'Brien and Azrin, 1972; O'Brien, Azrin, and Bugle, 1972; White, Nielsen, and Johnson, 1972; Whitman, Mercurio, and Caponigri, 1970). Within the family, parents have often been trained to modify their interactions with a problem child (Arnold, Sturgis, and Forehand, 1977; Forehand, Sturgis, McMahon, Aguar, Green, Wells, and Briener, 1979; Hall, Axelrod, Tyler, Grief, Jones and Robertson, 1972; McMahon and Forehand, 1978; Peed, Roberts, and Forehand, 1977; Tavormina, 1975) but much less attention has been paid to the nature of the interactions among mentally retarded children and their siblings (Grossman, 1972; Lavigueur, 1976; Love, 1973; Miller and Cantwell, 1976). However, sibling interaction should not be ignored since siblings may contribute greatly to each other's social development (Grossman, 1972; Lavigueur, 1976; Love 1973; Miller and Cantwell, 1976). According to Patterson (1980) family members are likely to respond to aversive behaviors with attention and counterattacking, with one individual eventually giving in to the other's demands, thus reinforcing the aversive behavior while creating a sequence of maladaptive behaviors. Since a handicapped child is more likely to engage in aversive behaviors than a non-handicapped child (LaVietes, 1978; Patterson, 1980; Tavormina, 1975) many coercive interchanges may occur within these families resulting in deviant behaviors in both the mentally retarded child and in the siblings as well.

It has further been suggested that these early disruptive interchanges may have adverse long term effects on the siblings, especially the sisters (Farber, 1959, 1960; Farber and Jenne, 1963; Gath, 1973, 1974). Based on interviews of families in which there was a mentally retarded child it was found that sisters often have increased child care responsibilities for the mentally retarded child (Farber, 1959, 1960; Farber and Jenne, 1963; Gath, 1973, 1974). According to Farber's reports the sisters become confused about their role in the family (are they a child or a parent?) and subsequently become angry and frustrated. Their anger affects their relationship with their mothers, possibly leading to later personality problems. Farber's findings further suggest that the sisters spend less time with their peer group because of the increased responsibilities at home and thus may be less well socialized within the peer group. Gath's findings that sisters of mentally retarded children are more likely than other girls to engage in antisocial behaviors, especially at school, seems to support Farber's speculations. Therefore, it is important to be concerned about the social development of all the family members when one of the children is mentally handicapped.

The following study was designed as a preliminary investigation of the nature of interactions among siblings in a family in which there was a mentally retarded child. The children were asked to discuss their perceptions of the mentally retarded child's problem behaviors and how they responded to these behaviors. Then, they were taught how to modify their interaction so as not to reinforce disruptive behaviors while reinforcing other non-disruptive behaviors. Finally, they were asked to describe how they felt about themselves and their mentally retarded sibling, and about the program in which they had participated.

Method

Subjects

Two white, intact, middle class families, each with a child enrolled in a special education facility for mentally retarded children in Baltimore participated in the program. Family A consisted of a son, aged 16 years, who was enrolled in the special education facility; another son aged 15 years; and two daughters, aged 8 and 10 years. Family B consisted of a son, aged 12 years, who was enrolled in the special education facility; two other sons, aged 14 and 15 years; and two daughters, aged 10 and 16 years.

Procedure

Target behaviors. In order to assess the problem behaviors an initial interview was conducted with the children in each family in which they were asked to indicate behaviors of the mentally retarded child which were aversive to them. The interview was conducted with each child individually, and they were also asked to describe how they reacted to these behaviors. Following these interviews the children's responses were discussed with the parents to obtain their assessment of the problem situations.

The following criteria were used to select a target behavior. The behavior had to be one that all the children in each family perceived to be a significant problem, which reportedly occurred frequently. Also, the behavior had to be one that the children seemed to reinforce by attending to it (such as reprimanding the child or telling the parents) or even by counterattacking (such as yelling at the child or fighting with the child). Finally, the behavior had to occur when all the children were together.

Using these criteria it was not difficult to select a target behavior for each family. As suggested, the children talked about several aversive behaviors which they reinforced inadvertently by attention or counterattacking. Only two of the children reported attempts to ignore the behavior. Also, although each child complained about aversive interactions unique to him/herself and the mentally retarded sibling, there were aversive interactions common to the family members. Children in Family A basically complained about disruptions occurring during TV viewing and referred to their brother as "showing off" during this time. So for Family A the target behavior was operationally defined as follows:

> show off: Anytime M takes something that someone else has without permission: such as turning the TV channel in the middle of a program; or taking a pillow away from someone; or calling the dog away when someone else is already playing with her. Also each fight with M (hit, kick, or series of hits, kicks, etc. initiated by M) was counted as an instance of show off.

Children in Family B complained of disruptions during breakfast due to their brother's talking loudly, repeating questions and interrupting conversations. This behavior had resulted in having their brother eat breakfast with his mother in a room separate from the rest of the family. For Family B the target behavior was therefore defined as follows:

> chatter: talking which is not related to the ongoing conversation and/or which interrupts the conversation and/or any talking which is non-directed (It is not a request for something that he doesn't already have or that he needs)

Training and modification of behaviors. Following the interview the children were given an essay concerning some principles of behavior modification (how to reinforce appropriate behaviors and to ignore inappropriate behaviors) and the importance of observing and recording behaviors. The essay was discussed with the children. A week later the definitions of the target behaviors and the observation and recording procedures were explained to the children. Children in Family A were instructed to record each occurrence of show off behavior between 8:00 and 8:30 p.m., which is when TV viewing usually occurred. Children in Family B were instructed to indicate during each 1-minute interval during breakfast time whether or not chatter occurred. A practice session using role play was conducted until 100% agreement was reached, indicating that the children understood the definitions and procedures.

On the following day the children began to monitor the behaviors to establish a baseline. An ABAB single subject design was used to evaluate the effectiveness of the program. During intervention the children were told to ignore the target behavior and to attend to other appropriate behaviors. For Family A an additional procedure of allowing the retarded child free time to choose and direct activities on those days when he did not show off was included. When the child indicated that he was not interested in free time the procedure was changed to one in which on days when he did not show off he received a star on a page in a notebook which was signed by himself and his siblings. During the reversal phase the children were given instructions for providing noncontingent reinforcement to the target child. The children kept daily records of the occurrences of the target behaviors and their responses to those behaviors, as well as weekly graphs of the behaviors. The supervisor met with the children once a week and contacted them by phone daily to discuss problems with them and to reinforce them for carrying out the procedures correctly. At the end of the program the children were asked to fill out a questionnaire concerning their attitude towards the program, themselves, and their siblings.

Results

All three of the children agreed on the occurrence of this behavior on 78% of the days, and two of the children agreed on 98% of the days. During the first baseline show off behavior occurred on 47% of the days with an average of .96 behaviors per day; during the first intervention the behavior occurred on 36% of the days with an average of .42 behaviors per day; during the reversal phase the behavior occurred on 50% of the days with an average of .41 behaviors per day; and during the second intervention the behavior occurred on 14% of the days with an average of .14 behaviors per day. When combining across replicated phases the probability of having two consecutive days on which show off behavior did not occur was significantly greater during the intervention phases (.73) than during the baseline phases (.38) with $z = 1.86$, p. .05. Inspection of Figure 1 shows that this finding is due to the fact that, despite the variability of show off behavior, it was only when the treatment effect occurred that it was unlikely for show off behavior to occur again on subsequent days.

Interobserver agreement was only checked twice (number of intervals agreed upon divided by agreements plus disagreements multiplied by 100). On the first occasion it was found that there was some confusion concerning the definition of chatter which was subsequently clarified. On the second occasion there was 100% agreement. It is clearly shown in Figure 2 that chatter began to decrease during the intervention phases as opposed to the baseline phases. Across the four phases the mean level of chatter behavior varied from 76% of intervals during the first baseline; to 52.13% of the intervals during the first intervention; to 51.63% during the reversal phase; to 50% during the second intervention.

On the final questionaires all the children from both families indicated that they believed that the program had been effective. Further, they indicated that they would continue to use the skills they had learned and that in general they had developed a better attitude towards their mentally retarded brother.

Discussion

As suggested by Patterson (1980) it was found that mentally retarded children do engage in aversive behaviors which the siblings are likely to attend to and counterattack. Thus, the aversive behavior is likely to be maintained while the siblings engage in maladaptive behaviors in response to the aversion and a chain of disruptive, deviant behaviors results. However, social learning theory suggests a program for change, which was illustrated here. The siblings were able to modify their interactions, resulting in a decrease in disruptive behaviors. Thus, the program had immediate positive effects, and the children were pleased with the outcome of the program. It is important to ensure that these positive effects are maintained and to be optimistic about positive long term effects. However, since still very little is known about the relationship of early family environment to later personality adjustment efforts to study this relationship should be continued.

Despite social learning theory's usefulness in understanding social development and mechanisms of change in order to completely understand and predict an individual's behavior one must take into account the individual's perception of the situation. This point is best illustrated by the example of show off behavior. According to the dictionary "show off" means to "display ostentatiously" (American College Dictionary, 1967). Perhaps this was indeed an accurate perception of their brother's behavior. He had indicated on several occasions that he know that he was the oldest, but he complained that he was not treated like the oldest. His siblings reported that he often tried to outdo the others, but usually failed. Was this child trying to impress others with his status? Was he trying to assert his authority by forcibly taking over a situation? Such an interpretation does not seem unlikely. In any case, we need to develop thoughtful and sensitive ways to help this child, and others like him, to cope with frustrations and disappointments due to the knowledge of their own limitations.

Social development does not occur within a vacuum. It is only through interaction with others that social behaviors and perceptions of social situations are shaped. Any individual, then, affects, and is affected by the behavior of others. Thus, when a "problem" child is identified we should be concerned about all the family members. Since the earliest interactions and perceptions are formed within the family unit, this is a rich context in which to study the relationship of early experiences to later social development. Such studies would not only add greatly to our understanding of social development, but will also further suggest ways to help problem families achieve more positive interactions.

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EXPLAINING DIFFERENCES TO CHILDREN

JoAnn Giglio

I'd like to begin with a little story which I came across in a book on disabled children. It is my favorite story about how a child - left to her own devices - interprets her own differentness.

Cindy's parents sought advice from a child psychiatrist when she was about 3 1/2 years old. Cindy had been born with a slightly-deformed and blind left eye. Even though they had observed her before a mirror moving her hands in front of each eye, they never talked about the eye to the little girl. Now that she was almost four, they wanted the doctor to help them discuss this with her.

I'd like to stop here and make some observations:

1) Their silence had not kept her innocent.

2) Waiting did not make the moment of truth any easier.

3) I would be willing to bet that avoiding the topic so completely must have involved avoiding many things - even games like peek-a-boo.

The psychiatrist ended up seeing the little girl until she was seven. He tells two stories that I want to share with you. Once when they were talking about how she felt about her mother, the doctor said he knew that all little girls had angry feelings about their mothers. She told him he did not understand - with her it was different. When she wished her mother dead, she really wished her dead. Again, the doctor said he thought it was this way for all little girls. Cindy was adamant! For her, it was different! The doctor asked if it was because she had so many things to be angry about. She said no. It was because her eye was different. She was different and so her anger was different.

The other story he tells is that during therapy, when sadness would have been appropriate, Cindy either began head-rocking or left the office to go to the bathroom. She said she could not become sad because she couldn't cry because she didn't understand about "eyewater."

Several times she did cry, but still she complained constantly that she could not be sad because she could not cry. She claimed that other things - like masturbation - were necessary to defend herself against sadness.

One time she was talking about a wish to be reborn with two eyes that could see, and the doctor asked her why that was so important. She burst into tears and ran from the room.

She returned promptly - quite happy and pleased. She had gone to the bathroom and in the mirror had noticed that both eyes had cried. She WASN'T different about the eyewater! Her eye was different just because it couldn't see. She said that what was most important was that her feelings were not different. It was just the sightedness of one eye that was different.

I had a small example of that myself this week with my son. He has Spina Bifida - wears leg braces and uses crutches to walk. He has a shunt in his head to handle the spinal fluid and he has no bowel and bladder control. Other than that he is not at all different!

Well anyway - he wasn't feeling too well last week. He was tired - his urine had a strong odor and was thick looking. Finally he had pain after catherizing himself. I had suspected a urinary tract infection so I was glad to have my "diagnosis" confirmed. The scariest thing is worrying about his shunt, so I was also relieved that all the symptoms were so clear. I told him he probably had a urinary tract infection and we would go have it checked. He just wouldn't let go. He kept talking about the pain - and suggesting elaborate reasons why he might be hurting. I dealt with each suggestion separately and then finally, exasperated, (and you might want to pay particular attention to the way I dealt with this since I am here as the expert in dealing with children) I shouted, "MIKE, YOU PROBABLY HAVE AN INFECTION. THAT'S IT - THAT'S THE WHOLE EXPLANATION. ONE TIME I HAD A PAIN WHEN I WENT TO THE BATHROOM. SO I CALLED UP THE DOCTOR AND SAID, 'DOCTOR, I HAVE A PAIN WHEN I GO TO THE BATHROOM' AND HE SAID, 'YOU PROBABLY HAVE A URINARY TRACT INFECTION'".

Mike said simply, "Oh, I didn't know other people have this pain. That's okay then. I just didn't know." He was so instantly and visibly relieved that I felt awful that I had been so impatient. It made me think of Cindy and the struggle to understand what is normal and what is different.

You know, really, we are all the same way. After something happens to us - a death, a divorce, a disappointment - we get new feelings and we experience surprising reactions and we need to test them out to see if they are normal. We join self-help groups and learn that most people feel thus and such a way when they lose their job. Or we read Dear Abbey and feel reassured to read that other women feel useless when their children leave home. There is comfort in learning we are not odd or disgusting. In fact, I think for most experiences, it is not the event itself which causes us the most anguish. It is the unexpected emotional reactions we find in ourselves. Perhaps we feel guilty or ashamed or embarrassed or inadequate or depressed or angry; all the things we are here to talk about in the lives of siblings. When we are sure of ourselves, we deal matter-of-factly and confidently. When we are unsure that our emotional responses are normal, we very often don't deal with things at all.

I think you can contrast the two examples I just told you. Cindy's parents were filled with grief and guilt and uncertainty. They never dealt with her at all. I was sure of myself regarding Mike's infection and dealt, not only matter-of-factly, but with added exasperation. While I don't recommend exasperation, I do want to point out that it is in such spontaneous naturalness that children get the real message. The message is this: this is routine, regular, open; we can talk about it; no one is embarrassed or ashamed; no one is whispering or being evasive; in fact, I am SHOUTING!!

Let me point out, however, that I *was* dealing with something very ordinary, and Cindy's parents were dealing with blindness. It is ordinary to have an infection, it is not ordinary to be blind. One of the reasons it is socially acceptable to have an infection is that it came out of the closet. Some of your best friends will admit they have a urinary tract infection - possibly so you will not even consider that they have herpes! But whatever the reason, we can look around us and put a kidney infection into perspective. We simply don't know how to do the same with disabilities. And if *we* can't do that, how can we expect Cindy to do that? Or Cindy's brother?

When my son was born I was embarrassed. It's a bit hard to admit that. Most people expect the mother to be sad and grief stricken - but I was embarrassed. It was one of those unexpected emotional reactions I was just talking about. I knew everyone would be fussing and I'd just as soon not be the center of so much attention. I wanted to be alone - not on display - as I composed by reactions. But I had learned a trick early in life. If you don't want to draw attention, be open and natural. Sneaky kids, mysterious neighbors, hidden packages and whispered secrets draw the most attention and the most bizarre speculation! I resolved to be open with things as quickly as I learned about them - before I had to make elaborate decisions about how to "manage the information." I am normally very private about personal care. I lock the bathroom door and turn the lights off to get undressed - but I went public with Mike. I decided that he and my other children were going to read between the lines. If I hid catheters from sight and never talked about them - I would feel isolated for a good many hours a day. And I would also be telling my children that no one could know about such shameful procedures. *Privacy was a luxury that Mike couldn't afford*. He would have a lifetime of hospitalizations, medical exams - perhaps even institutional care. He needed to know that other people could be trusted with the truth. What a disservice it would have been to him to make him think that only Mommy and Daddy could care about him at his most honest level.

You know it is fascinating if you watch T.V. or movies. Even an ordinary director can make the entire audience empathize and identify with whatever character the author wants to be appealing. They use all kinds of non-verbal techniques to win the emotional support of the viewers. A little tear, a quivering lip - you know what I mean. But think for a minute just what they do. They give you behind-the-scenes information. They will show someone being scared and then putting on a brave front. Or they will make you afraid and they will be sure that you know the hero has seen what you just saw. Then whether or not you see his scared face, you KNOW he's scared! When they give you enough information they can guarantee your empathy.

I think that is a good thing to remember when we think about telling children about differentness. If you give enough information - within the context of things they can identify with - if you give factual and emotional raw material - you rob things of bizarre stigma. The craziest things become routine and understandable.

I'm leading up to one of my most effective ways of telling my own children - and other children - about Mike. I took him to school for Show 'N' Tell when he was very young. I brought old casts - braces, toys, photos, posters of the central nervous system - everything I could think of. I would explain the disability and model ways of interacting with a disabled child. My own child had status because I was there and no one else had a brother interesting enough to teach about. My daughter told me (as [illegible] preparing for this presentation) that those classroom sessions taught her the most. My children gradually took pride in the knowledge and skills they had acquired because of Mike. Occasionally they babysat at Easter Seal during parent conferences and eventually two of my children got jobs at a day camp. On their applications they wrote that they had specialized knowledge about handicapped children and they wrote it with pride.

Over the years, wherever we are in the community, children come up to us to say hello. Their parents get a stricken look for a moment as the child reacts and gestures toward us. But the child will quickly say, "Oh that's Mike. Remember I told you his Mom brought him to school." I can see the parents relax.

Also over the years, friends and neighbors have been willing to take him places, and even the school asked us to place him there rather than in a special school. At parent groups, others have been astonished when I say these things. I really think it is because I have been so open that I have enabled others to deal confidently with us.

I think that my children heard me telling people about Mike all their lives and it had three significant effects: 1) the repetition helped them to learn the information accurately as they were ready to assimilate it with more complexity; 2) the flood of information had a desensitizing effect on me and on them; 3) they found it helpful to watch me modeling a socially acceptable way of dealing with the outside world.

I have one more point I'd like to make. Please listen to your children. They are the best barometer of how the world is viewing your disabled child. Parents tend to be too tolerant sometimes, and too protective - or too uncomfortable - as were Cindy's parents. I was thinking about that as I was preparing this speech, and I went back to look up the story of Cindy. I wanted to know if she had brothers and sisters. I think it is significant that Cindy's brother was only 14 months old at the time the case was written, because you could have counted on an older sibling to say, "Her eye is weird." And that would have brought it all out in the open.

At such times I think it is wrong to deny what the child has observed. I think it is a good time to let your children help you figure out what you can do to make things appear less weird. One example of that in our case involved dressing Mike in his first braces. He was only two years old and the brace had a bar across his back that fastened across his chest. It had a band at the hips and another at the thighs. Of course, metal bars ran the length of the braces on each side of his body. The braces are made to wear under clothes but when we did that, Mike appeared to have a hunch back and deformed hips and bulky legs. So we tried putting the braces over his clothes. Then you could see there was a normally shaped body within a metal brace. It was easy to tell what was different and what was not.

Which is, of course, the point: siblings are great for keeping the normal parts normal! Tell them that! Compliment them when they deal well or when they are helpful. Help them to feel pride that they are so competent in situations which so many people find distasteful and uncomfortable. Value them for giving your handicapped child so much honest humanity to bump up against. We all need to test ourselves in reality. Siblings are the disabled child's first reality. What could be better?

A DEVELOPMENTAL PERSPECTIVE OF THE SIBLINGS OF HANDICAPPED CHILDREN

Judith Feigon

Karen Gronner

Part of the way we, ourselves, are shaped by our early relationships. Among these early relationships, those with our siblings are crucial. The importance siblings have for one another is seen in the areas of competition, hostility, and aggression, as well as in bonding, identity formation, and supportive feelings. Most often emphasized in normal sibling development are four factors: position, number of siblings, sex and access, spacing of the siblings.

Recently there has been greater recognition of the ramifications of sibling relationships. Professionals working with handicapped children have examined the impact of these children on their families with varying emphasis on the degree of stress on the siblings and often using as their base the factors cited above.

Farber (1959, 1960) was one the first to study systematically the families of handicapped children and, later, the effects on siblings. Since then the amount of research has been limited, with a marginal increase recently. The studies have used divergent samples, research questions and methodologies. Simeonsson (1981), who extensively reviewed the literature, characterized the dilemma in the following manner: ". . . findings are specific to the question being asked and the sample and reference involved. Conclusions may therefore not only be variable but have the appearance of inconsistency." (Simeonsson, 1981, p. 155). This does not invalidate the studies, but does limit their general applicability.

The conclusions of the studies have fallen into three categories: negative impact on the siblings (e.g. Breslau), no impact (e.g. Graliker), and positive impact (e.g. Farber, 1963). Factors measured to determine these effects were family situation, nature and degree of the handicap, and age, sex and birth order of the siblings. It is not our purpose to review the specific studies except to comment on the diversity and inconsistency of findings.

In contrast to research studies, there is a more extensive body of clinical literature. Personal accounts by siblings themselves suggest that the normal siblings are affected throughout their lives. Feelings and needs and the ability to express these vary, but all accounts reviewed illustrate an intensity of feeling toward the siblings. The articles themselves seem to be in some cases a cathartic vehicle as well as an educational one. The remaining clinical literature discusses case studies, clinical programs, and family dynamics.

The stress factors most universally cited in the literature include high parental aspirations, unmet needs, guilt about being normal, and role problems within the family (Schild, 1971). The responses of the normal siblings are generally viewed as influenced by the parents' ability to handle the situation, the meaning of the handicapped sibling to the child, the coping abilities of the child.

Both the research and the clinical literature point to a multitude of variables influencing the impact of the handicapped child on his siblings. In our effort to understand this diversity we have focused our interest on the child's repsonse. We did this by reviewing the existing literature as well as by record systematic observations of siblings in groups and individual programs.

Our clinical data as well as the literature reviewed led us to devise a developmental view of assessment. In this paper we will present this model, utilizing clinical data to illustrate its applicability.

Model for Sibling Adjustment

Our experience with the siblings* of handicapped children confirmed the variability of the their response and raised questions about differences in their coping abilities. Some children were able to proceed with normal development while others related to the presence of a handicapped sibling as a developmental interference. In order to evaluate this, the individual features influencing coping capacities needed to be understood. These features were identified as: the child, the stress, the coping response and the resultant behavioral outcome.

The term _child_ is defined as the normal siblings of the handicapped child. _Stress_ refers to the unpredictable impact created by the handicapped child. _Coping mechanism_ is the unconscious or conscious strategies the child utilizes in order to adapt to his situation. _Behavioral outcome_ is the outward manifestation of the child's coping mechanism which may be seen in either problematic or integrative outcomes.

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* Observations were made between 1973 and the present at the Dysfunctioning Child Center, an outpatient clinic serving handicapped children and their families.

Schematically these features influence one and another in the following sequence:

(PLUS) (EVOKES) (RESULTS IN)
CHILD + STRESS COPING RESPONSE BEHAVIORAL OUTCOME

This schema aids in initial assessment of the child and his situation. However, it alone does not convey the complexity and range of both stress and response. A recognition of the multiple dimensions of a child's functioning must also be included. This can be conceptualized in terms of four sphere, symbolized by concentric circles (Diagram I). The innermost circle represents the internal state of the child, and as the circles expands outward, they signify the child's broadening range of experience.

These spheres of functioning, which operate concurrently, consist of:

Intrapsychic:	Internal feelings and emotions which interact to form personality structure.
Interpersonal:	Relationships to peers and others in the environment.
Family:	Child's view of his own role and that of the others in this family constellation.
Cognitive:	Child's intellectual process and level of abstraction and how this translates into this world view.

The child mediates among the spheres with varying degrees of focus and levels of adaption. The stress cuts across all four spheres, evoking at the same time responses unique to each sphere, and this illustrates the complexity of the child's reaction.

To complete the model, the dimension of time needs to be considered. A developmental understanding takes into account the unfolding of needs and capacities. The developmental perspective stages in essence that there are specific tasks and resources available to a child at a given stage of development. These developmental stages are preshcool, latency, early adolescence and adolescence. Each stage brings variations in the tasks, the stress and therefore the ability to cope, shift and change over time. The child approaches each task or stress with age-appropriate strategies. The experience of having a handicapped sibling is different depending on age. The level of adaption within the four spheres varies and provides for a variety of responses within the individual child. This model, then, is a basis for assessment of the child and his needs.

Clinical Application

To illustrate this model, charts were developed for each stage of development. (Diagram II) The spheres of functioning are listed vertically. Factors influencing coping are listed horizontally. Examples given in the chart are of commonly identified themes, although individual children may or may not experience the same reactions.

To elaborate this, we will discuss the latency age chart. The general understanding of latency-age children is that they have past through the early developmental milestones of establishing a sense of self and separateness and now direct their developmental tasks to organizing their inner selves in relation to their increasing awareness of their expanding outer world. In latency, the child has a fairly well-established notion of roles within the family, both his own and that of another and has expanding explorations with the outside world. He experiences himself as initiator and recipient of increasingly complex feelings and events. For example, the birth of a handicapped sibling may be a severe disruption in established family routine. Children whose handicaps include erratic behavior or sudden acute medical needs lend unpredictability to the family atmosphere at a time when the latency age child relies on routine. Within his family, potential stresses include added responsibility in caring for the handicapped child and often displacement by him. Often parents expect the normal sibling to have a special tolerance and sensitivity to the handicapped child and consequently discourage normal sibling conflictural and rivalrous exchanges.

The coping mechanisms one might find in a latency age child include alignment with the sibling as having special needs: school problems or behavioral difficulties may develop. There may be alignment with the parents as caretakers. Another possibility is that the child may cope by firming up his own role identification.

Among the outcomes, one may see a child who exhibits special needs or one who is able to experience greater empathy toward others. There may also develop a pseudomaturity on the part of the normal child or a genuinely more nature and supportive relationship with the parents, without cost to the child's own integrity. We may see variations in the ability to cope with change, and finally, uncertainly and confusion with one's role versus role acceptance.

Cognitively the child's intellectual and perceptual skills are increasing and during this phase of development concrete reasoning is operating but movement toward beginning a abstraction becomes apparent over time. Here, then, the child is clearly aware of the sibling and his differences but the ability to conceptually integrate the understanding on a more abstract plane is lacking.

The child copes by thinking about his sibling's problems in a very concrete manner. He may be able to say, for instance, that his brother is retarded, he may know that he has Down's Syndrome, and he may even be able to list some of the characteristics of the syndrome, however, he lacks an in-depth understanding, and his ability to demonstrate his concrete knowledge may delude the parents and others into thinking that his understanding is greater than it is. Certainly, the latency-age child is well aware of the sib's differences.

Case Study

George, 11, was called to our attention by a hospital social worker who was involved with the parents around his two brothers who had cerebral palsy which affected both their mental capacities as well as their physical development. The older brother was non-ambulatory and moderately retarded an the younger brother was mildly retarded and physically more intact.

George, who was the middle child, exhibited increasing stress in seeing other of his brothers developing abnormally. He coped by denying the severity of their handicaps; this was evidenced by repeated references to mutual activities and expectations of things they would "all" do together. For example, he often talked about his brothers' driving the car some day, just as he expected to do, a very unrealistic expection. Intrapsychically the meaning of his brothers' handicaps needed to be denied, to ward off the anger, fear and guilt which periodically broke through his defenses in a disruptive manner.

In relation to this family, he coped by developing mastery. He placed himself in the position of bread winner, voluntarily contribution all his paper route money toward family expenses, forsaking any spending for himself.

His relationships with peers were limited. He rarely spoke of friends. When discussing activities, he would refer to his brothers as peers, "We played ball . . . .". It became evident that his commitment to "taking care" of his brothers surmounted any other relationships.

Cognitively, George was capable of explaining his brothers' conditions, describing to them the nature of their illnesses and limitations. Yet, his intrapsychic need to deny this initially confused us regarding his level of awareness and factual knowledge about their handicaps. As we listened to the child we became aware of the conflict. He could cognitively relate facts of the illness, but emotionally avoided any recognition of it.

This was graphically demonstrated in a family drawing in which he drew his non-ambulatory brother without legs and showed no conscious awareness of this. In fact, in subsequent conversations he spoke of his brother as ambulatory and alluded to playing active games with him.

Thus, as we began to think about George in the four previously delineated spheres of functioning, we found disruption in age appropriate development in all areas. George was isolated, having few outlets outside of this home. His peer relationships being limited to his brothers, did not provide the necessary stimulation. His school performance was below expectation given his seeming ability. This appeared to contain both elements of diminished investment as well as an identification with his brothers' reduced abilities. The conflict for this child seemed to center on wanting to identify with both caretaker and victim. His level of output was always mediated by both of these identifications and the conflict that ensued left him in a constant state of anxiety. He could not get angry at either parent or sibling and the denial of these feelings led to an inhibition of age expected pulling away from family.

Thus, the outcome for this child involved a compromise of this internal and interpersonal development to ward off the anxiety he experienced in relation to this brothers. This understanding was then helpful in treatment planning.

Discussion

In this paper, the normal sibling of the handicapped child is viewed in a multi-faceted way. The child's coping capacities are assessed within the context of his internal and external world. Fluidity of development is recognized as well as the innate capacity toward growth.

The model, when applied to a specific child, takes into account the uniqueness of his situation and yet allows for applicability to all children at varying ages. Some of the previously cited discrepancies in the literature are addresses by accounting for elements of time and area of functioning as variables that need to be identified and may fluctuate.

Making assessments of children more specific and less global helps in formulating strategies of intervention. Problems identified by sphere and developmental stage can specify the types of interventions as well when they should take place.

Summary

A model for Sibling Adjustment is pesented which includes spheres of functioning (location) and stages of development (time). The child is described as adapting to stress within the parameters of location and time. This is graphically and clinically illustrated and application of the model is given for the latency-age child.

DEVELOPMENTAL MODEL FOR SIBLING ADJUSTMENT

APPLICABLE FOR EACH DEVELOPMENTAL STAGE (PRESCHOOL, LATENCY, EARLY ADOLESCENCE, LATE ADOLESCENCE):

CHILD $\overset{\text{(PLUS)}}{+}$ STRESS $\xrightarrow{\text{(EVOKES)}}$ COPING RESPONSE $\xrightarrow{\text{(RESULTS IN)}}$ BEHAVIORAL OUTCOME: ______

problematic/integrative

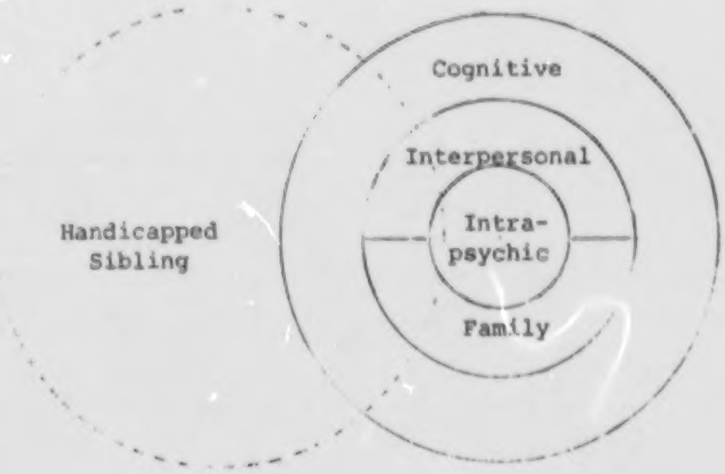
Cognitive
Interpersonal
Intra-
psychic
Family
Handicapped
Sibling

DIAGRAM I

ency 10 years)	Normal Developmental Task	Handicapped Sib* Stress	Major Coping Mechanism	Examples of Problematic Resolutions	Examples of Strengths
rapsychic	1) Continuation of separation individuation 2) Superego development consolidated 3) Character traits established	Increasing internal awareness of sib's difference	1) Identification 2) Sublimation of stress into other activities 3) Denial and disavowal	1) Psychosomatic complaints 2) Repressed feelings which inhibit productive activities 3) Feelings of emptiness, inadequacy and guilt 4) Unrealistic expectations and disappointment in sib	1) Enhanced capacity to use varying ego functions 2) Creative expression and internal motivation for high academic achievement 3) Increasing mobilization of intrapsychic energies expressed in positive attitudes toward sib and self
erpersonal	Increasing interaction with world (i.e. school, community, peers)	Increasing social awareness of sib's difference	1) Withdrawal from extrafamilial interactions 2) Denial of sib's existence or difference to others 3) Concern for sib and others	1) Isolation and lack of interpersonal relationships 2) Distorted representation of family functioning 3) Humiliation, embarrassment and disappointment	1) Ability to socially interact with others concerning sib and tolerance of differences 2) Positive caring relationship to sib
ily	Clearer concept of role of family and role within family and awareness of other family systems	1) Added burden of caring for sib 2) Greater parental expectations 3) Less predictability within family	1) Aligning with sib as having special needs 2) Modeling of parents as caretaker 3) Role identification	1) Child appears to have special needs also 2) Pseudomature adaptation 3) Difficulty coping with change 4) Role confusion	1) Greater empathy towards people 2) Supportive relationship to parents 3) More resilience to change 4) Role acceptance
nitive	Increased cognitive and perceptual skills: concrete operations	Increased awareness of sib without consistent conceptual capacity to integrate understanding	1) Conceptualization on a concrete level 2) Awareness of sib as different than other children and self	1) Confusion of sib's abilities and responsibilities 2) Intolerance of difference	1) Acceptance of ambiguity 2) Greater tolerance and conceptualization of difference

*Sib refers to handicapped sibling
Child refers to normal sibling

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DIAGRAM II

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A FAMILY SYSTEMS LOOK AT THE DEVELOPMENTALLY DISABLED

Marilyn Jaffe-Ruiz

The topic upon which we are about to embark is a difficult and often understated one, and yet I feel very strongly that the time has come for us to play a part in the care of this special population.

As a psychiatric mental health clinical specialist before my colleagues and peers, I feel honored and as the older sister of a developmentally disabled brother I am challenged to present a paper which I hope is informative, interesting and coherent while being personal.

For purposes of this paper I am using the words retarded, developmentally disabled and handicapped persons almost interchangeably. In all cases I mean those individuals born into a household who are exceptionally different and who will not mature intellectually or socially to an average adult level.

I have also chosen to not speak to the "pleasures" in raising such a child (even though there are many). As a faculty colleague said to me in discussing this presentation -- "Oh, Marilyn, I hope you're not going to do the 'we're so much better for this experience' bit." "No, I'm not. The pain is too great."

Talking about families is particularly difficult. All of us come from a family and most all of us are part of some family group currently. Families stir our passions as nothing else can and for most of us our thoughts and feelings about our families are highly charged emotionally. It is often hard to rid oneself of the myth or desire for the "Happy Family" like the ones depicted on TV: Father Knows Best, Family, The Waltons and Eight is Enough, where mother and father are wise, compassionate, understanding and well dressed and the children are intelligent, aware, sensitive, active problem-solvers with a great sense of humor, where the most physicial problem depicted is a child with eyeglasses.

Most families do not live up to those portrayed images and especially the families with a developmentally disabled child as a member. A Difference In The Family, the title of a book by Helen Featherstone (1981), aptly describes the family which has a member a developmentally disabled child. Until recently literature on this topic dealt almost exclusively with the child itself, diagnosis, treatment and institutionalization.

Little, if any, literature addressed family issues, especially the system as a whole, the marital subsystem or the sibling subsystem.*

The Family as a System

There is currently a move from a "change the child" approach to looking at the whole family (Grossman, 1972).

Early conceptualizations of parental responses were psychoanalytically oriented focusing on guilt, denial, projection and rejection. Parents were placed in the role of psychiatric patients in order to get help and the help was often pathology oriented (Monolascino, 1970). More recently the psychoanalytic underpinnings are used to help parents cope with the stress of realistic demands and burdens placed on the family system. Efforts are made to support self-help groups of parents and siblings and to provide concrete and direct services.

The family as a system is seen as an integral whole of interrelated components which is more than and different from the sum of its parts. The identity of the family reflects the common or shared identities of its consitutent members. The family name, socioeconomic status, cultural/ethnic background, number and kind of members also help to define a particular family (Ackerman, 1973). A family with a retarded or disabled child often becomes known based on that one attribute; the family of a "mongoloid child" or "hydrocephalic" or "deaf" child. Negative connotations ascribed to difference in this society result in the whole family being stigmatized.

The parts of this system may be viewed as the family system itself, its component members, and the total environment. For the family with a developmentally disabled child the health care and educational institutions often play a tremendous role in the life space of that particular family. Professionals are involved in diagnosis, treatment, denial and/or facilitation of acceptance at various stages along the way. At any event, the family is usually more closely involved with health care, social service and educational workers than a family without disability. This is an important consideration if one is concerned with family boundaries, independence/dependence, and the role of the adults in the family. Long waits, special and time-consuming procedures and lack of services can exacerbate the hurt and anger of the family.

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* I am using parents to mean male and female adult members of the household. In the literature reference is made to the fact that often the mother is the one involved in help-seeking activities. (Featherstone, 1981).

Alterations in the physical environment as well help to make these families "different". Wheelchairs, applicances, compensatory devices for eating, drinking, sleeping and toileting are as much a part of many of these families' homes as high chairs, toys and bicycles are in other homes. Distrubed sleep wake cycles, difficulties in feeding and toileting all contribute to family fatigue, fear and anger.

Managing a family then, with a great deal of its energy being devoted to those activities of daily living which in other families are more or less automatic, makes a difference in family energy reserves for self actualization, growth and differentiation.

Often the day-to-day activities are enough to drain people of all their strength unless sufficient resources are available. Financial as well as material and supportive supplies are crucial to family functioning. Schools, day treatment programs, home care and respite care are some of the ways families can get relief.

A change in any part of the system reverberates throughout, all the while moving toward greater complexity and diversity (if the system is an open one) or stagnation and dysfunction (if the system is closed). This is an especially troublesome area for families of the developmentally disabled. If the family progresses through the family life cycle, e.g. as described by Duvall (1977), a certain developmental progression is assumed on the part of each member, particularly children. How does a family get to the "launching" stage if one (or more) of their children has a mental age of three, four of five? How do parents cope with their own parents' aging and eventual death if an offspring is retarded, blind and has cerbral palsy and lives at home? How do parents reconcile anger, despair, sadness and grief around a child who may be autistic, developmentally impaired and have real behavior disorders with knowledge of inadequate, often treacherous, institutional conditions?

How do the siblings cope with their own teenage years while perhaps feeling stigmatized, guilty or socially hampered by a developmentally disabled sibling? How do they plan, organize and envision the progression of their own lives while lurking in the back of their minds is the fear, worry and actuality of assuming responsibility for a handicapped sibling? How do they cope with anxiety about aging parents and illness without simultaneous concerns for the disabled sibling?

How do parents and children together arrange family life to be able to differentiate, actualize, strive for growth and independence while experience "chronic sorrow"? (Olshansky, 1962)

The normal changes of family life which are stressful for most people are further complicated in exceptional families. Changes in addition or loss of members through marriage, birth, death, adoption, separation or divorce, as well as intrapsychic and interpersonal changes are often wrought with additional anxiety and turmoil compared to average family cohorts. Imagine a 72 year old widowed mother faced with emergency surgery while worring about the thirty-three year old son with Down's Syndrome who lives at home with her. Imagine her 38 year old daughter, the only other child, trying to negotiate care for mother, brother, her husband and herself while maintaining professional career, other family an self obligations.

These problems are further compounded by a modern, urban, technolocially advanced society where families are small, the extended family is distant and one needs to rely on bureaucratic social services or have a great deal of money in order to obtain assistance.

By the same token the family unit needs strength and energy to cope with its special needs and its "normal" needs. Members still need to work, have recreation and leisure, make love, and have friends. Family life which enhances self-esteem, openness and good communication are as important here as in any other family. These families, too, need to provide satisfaction of survival needs and developmental needs (Ackerman, 1973).

System Needs of the Family of the Developmentally Disabled

The needs of the family vary with time and over time. Initial diagnosis and planning are the crucial first steps a family must cope with, simultaneously long term thinking and planning, while on the family's mind, usually takes a back seat.

The family's interpretation of the event of the birth of a disabled child is a important as the event itself. Is it considered a stigma, blemish, sin, deviance, challenge, blessing, special opportunity, trial or test? These interpretations are culturally determined. It is reported that large families and Catholics, who believe in the sacredness of life, respond more to the handicapped child as a blessing. The Hutterites do not view the child as a stigma either but rather as one of the community with special needs (Grossman, 1972). By contrast, Jewish, Protestant and smaller families have more difficulty accepting the retarded child and are more likely to perceive the situation as tragic, sinful, or burdensome (Grossman, 1972).

The shock, denial, anger and grief parents first experience places them in a vulnerable position vis a vis health care professionals. There is a tendency to "doctor shop" in efforts to hear that what they have often suspected on their own is not true. Information is often withheld on the part of the professionals because of their genuine lack of knowledge and sometimes because of their difficulty in handling a very painful situation.

Parents need information and by all accounts have appreciated those professionals who took the time and had the concern to share their findings with relevant information in a sympathetic, kindly and honest fashion (Featherstone, 1980; Fotheringham, Skelton, Hoddinott, 1971).

Children also need accurate information and knowledge. An atmosphere needs to be created which encourages children's natural curiosity. Family discussions are necessary in which questions, feelings and worries can be aired. This is best done in the family or in peer groups of other parents and/or siblings in similar situations (Grossman, 1972).

The stress of having a disabled child can be partially adapted to by having clear-cut guidelines regarding the physical care involved, resources and services available and opportunity to express feelings including hurt, disappointment and anger without fear of retribution, relatiation and withdrawal of services. Counseling efforts can be directed to identification of immediate concerns including the needs of, and effects on, the other children. Parents report that their main concern might be around getting a child to eat or to sleep through the night, initially, and they are not ready at that point to consider long range needs and options or needs of other children.

However, the question of residential placement or institutionalization often comes up early on, in fact even at the time of birth and before confinement is over. This is more likely to happen if the problem is immediately evident as in Down's Syndrome or hydrocephalus. Most parents are not in a position to make a decision at that time and often are pressured by "well meaning professionals" who view the disability, though uncertainly, with regard to eventual developmental possibilities, pessimistically.

Many parents do not know that anything is wrong at birth but only later on when their child does not "measure up" to other children. For still others, it is not known until the child is a pre-schooler. In some ways the less visible and milder difficulties are more difficult to accept because of the ambiguity in comparison to the obvious problems of the moderately to severely disabled.

The expression of the pain and grief experienced by the family during the early phase of the child's life with them varies. Jacobs reports fantasies of infanticide as an altruistic gesture and concommitant fantasies to suicide of parents as common in a group of parents he studied in

California. These parents were frightened to think of the child outliving them and viewed death as a blessing (Jacobs, 1980).

The "novelty shock" which typifies the birth of an atypical child has to do with shattering of expectations of a "perfect" infant who looks like the parents and will grow up healthy and successful (Wolfensberger, Kurtz, 1969). Reality stress soon follows with all the questions, worries and fears involved in raising a handicapped child. Concommitantly, the parents are struggling with the value conflicts which include cultural attitudes, theirs and others, to deviance. Parents report feeling frightened, angry, disgusted, pitying and repulsed by their offspring which is antithetical to being a "good" parent and human being. Other parents report feeling "cursed" or that this is their burden to bear, or some appropriate punishment for past sins.

This is not to say there is not a small group of parents who feel blessed to have a child, love it freely, and in fact may have chosen a disabled child in adoption, foster care or continuing a pregancy after amniocentesis indicated abnormalities. Religious affiliation is a strong determinant here.

Other fears revolved around the possibility of eventual institutionalization in places with poor facilities (Willowbrook type situations). Institutionalization, when considered, is viewed as beneficial for the family's sake even though attempts are made to rationalize the situation as better for the child to be with others like him, or to protect other siblings. In fact research has not borne this out conclusively and there is strong evidence that the handicapped child develops better in a home atmosphere and siblings are often threatened by institutionalization of the retarded sibling -- could that happen to me?

Parents fear adolescence and adulthood with the burgeoning sexuality of their child or their own lack of tolerance for a chronologically and perhaps physically adult sized person behaving at a young developmental age. On the other hand some children exceed the wildest dreams of parents and professionals and can live productive, self-sustaining lives including employment and marriage.*

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* A family with a five year old hydrocephalic child visited relatives bringing wheelchair, walker and other paraphernalia to assist the child's ambulation. However, one family member or another more often than not carried the child, who was quite heavy, from one place to another. I wondered how long they could do that? And the effect it had on her older brother?

Some families cope by taking it one day at a time and try not to plan too far in advance. This is easier when the child and family are young. However, as parents, other siblings and the handicapped member age, plans need to be made for everyone's well being, including financial planning and guardianship. The fact that the retarded child does not grow up in the usual way restricts the family to a current time perspective, making them delay the need for long term planning.

There are differences in how fathers and mothers react. Both feel worse about boys initially which probably reflects societal attitudes toward males who bear the family name and generally are more valued. Jacobs reports that fathers adapt less well, especially to the same sex child (1980). Fathers were reported to be more overprotective and solicitous which tended to isolate the child and family from normal socialization processes.

Mothers usually have very close ties between self and the handicapped offspring. Frequently she only talks about her feelings to grandparents or older normal siblings and rarely to her husband.

The marital dyad usually experiences retricted social activity in that they rarely go out without the child and tend to rely heavily on grandparents and older siblings. The stress often burdens the marital dyad and there are reports of separation, divorce and "walkouts".

Even though it is said that adversity brings people together and strengthens bonds, the particular problem of giving birth to a less than perfect or at least ordinary child shatters many people. If the father is troubled by low self-esteem to begin with, then a retarded child might confirm his worst fears.* If a mother has felt dependent, unattractive and tied down, a handicapped child might accentuate her feelings. In any event, the capacity to cope with a shared problem is weakened if previously each relied on the other to shore them up and now each is in so much pain that all they can do is lash out at each other or be miserable together.

Family members often try to protect themselves and each other from the hurt and the burdens. This can produce a severe sense of estrangement, isolation and loneliness. Each feels guilty, partially to blame and responsbile while desiring to cope as effectively as possible, even if one fantasizes running out. Creativity, jobs and careers are often sacrificed by the parents. The prolonged early child care, pain, anger, fear and fatigue can serve to sap the energy that would ordinarily be channeled into productive activity.

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* A young Jewish father of 45 died of myocardial infarction shortly after his son with Down's Syndrome turned 13. The final realization that his son could not become Bar Mitzvoh was a crushing blow.

The siblings of the handicapped experience many of the same responses with the additional stress of trying to compensate for their disabled sibling in order to make the parents feel better. This can contribute to a loss of their own identity, specialness and uniqueness of family life revolves around the exceptional child. Fantasies of changing places with the disabled sibling in order to please parents is common.

Little work has been done on the effects of developmental diabilities on the siblings of the developmentally disabled. Frances Grossman, Brothers and Sisters of Retarded Children, is the most recent attempt to systematically study college-age siblings of the mentally retarded (1972). By virtue of the fact that her subjects were all in college and volunteered to participate in the study has evident inherent bias, yet it is the most up-to-date and complete work to date. Future investigation certainly warrants study of other populations, includings older siblings of the adult retarded and non-college populations.

Jacobs (1980) found for the most part that siblings were sympathetic and helpful. Many go into the helping professions - special education, nursing, social work or medicine. Both Jacobs (1980) and Grossman (1972) report evidence that siblings in two child families have more difficult time than in families with many children.

This would make sense if one considers the special function of a sibling subsystem to share the work of the role as children to parents. A handicapped sibling usually cannot offer the support, competitiveness and sharing that happens in other families. Many of the siblings sampled, especially of a two child family, spoke of the longing to have a normal brother or sister to share life with (Grossman, 1972).

Siblings who overall "benefitted" from having a retarded sibling felt they had gained a greater sensitivity to and understanding of people with more compassion and less prejudice. They also appreciate their own good health and intelligence (Grossman, 1972).

Siblings who were "harmed" had unresolved guilt, shame, and resentment toward parents who perceived as having neglected them. They were more preoccupied with the handicapped sibling and experienced the family stress more acutely (Grossman, 1972).

Siblings, when informed of the retarded child sibling, respond in many ways. There is fear of some damage to themselves as well as intense curiosity about the disabled child. The parents tend to set the tone for how to cope, e.g. if parents are denying the handicap, feel ashamed and stigmatized, chances are other children in the family will suffer limits to their curiosity and restriction in expressing their feelings.

It is common for most siblings to argue, fight and vent aggression one to another. How families cope when the normal child calls his retarded brother or sister "stupid", wants to exclude him from his play activities or is angry because his homework has been scribbled on, can make all the difference in the world in fostering the normal child's sense of self-worth. Frequently the child is squelched and winds up feeling rejected even if he intellectually can understand why his parents are reacting in a certain way.*

The family interfaces with the larger society often through their children who go to school, play with peers and in general get around. This child's sensitivity to the family mood will influence how he gets along with others and how he explains his family to others. The "others" of course teachers, friends, parents of friends and neighbors will respond based on their own perceptions, values and prejudices, e.g. a sixth grade female candidate for the S.P.'s (Special Progress or Rapid Advancement) with retarded brother was told by her sixth grade teacher that she was recommending the girl for the S.P.'s "for her having a 10.5 grade reaching level and a tested 10 of 132.

A college age white female brought a Black girlfriend home for the weekend. A neighbor commented to the youngster's mother - "Isn't it bad enough you have a retarded child without bringing Black people into the neighborhood?" Other children's parents may also limit their children from playing with the sibling of a developmentally disabled person.

Social class, cultural background, family size and religion were factors influencing siblings in response to the developmentally disabled in much the same way as it had their parents. Upper socio-economic class siblings whose families had sufficient means to obtain resources were most likely to be shielded from the detrimental or "inconveniencing" effects of the handicapped sibling. Their siblings had medical care, educational opportunities, domestic help and private institutionalization where needed.

Females were more involved in child-rearing activities and were closer to the experience of their mothers with regard to the effects of a handicapped child on the family than male siblings - reflecting our cultural sex role expectations. These same females had a higher incidence of anger and resentment toward their mothers for putting them in a position of mother surrogate.

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* A young women recalls being nine and calling her three year old Down's Syndrome brother an "idiot", as children of that age are apt to do, and being horrified at her parents' intense anger at her for saying such a thing.

Siblings who were older than the retarded child coped more effectively than those who were younger than the handicapped sibling. Older siblings identify with parents whereas younger siblings were competitive and then felt guilty as they surpassed the older but handicapped brother or sister (Grossman, 1972).

Those college students who were from the lower socioeconomic class were more involved in the child care responsibilities. The handicapped child was experienced as a financial and emotional drain which precipitated more family crises.

The girls were quite involved in care of the disabled child and often felt they knew better than their mothers how to care for the child. They would speak of their families with almost clinical detachment and many went into the helping professions. The males were less involved at home and usually were working outside the home while in school. Both experienced family stress and tension with little opportunity for verbalization at home (Grossman, 1972).

Siblings from larger families had a better adjustment. Those from two children families experienced more pressure to achieve, felt responsible for success and felt more responsibility for the parents' self-esteem.

Long Term Needs

Chronic sorrow, as described by Olshansky (1964), goes on for the duration of the child's or parents' life with each passing year. When an expected developmental milestone is not attained the pain, loss, grief are accentuated. The "normal" developmental process of moving from helpless dependency to independence is thwarted. A "childlike" adult is vulnerable to the decisions of others without input.

Communions, Bar Mitzvohs, graduations, weddings are not in the repertoire for the most part in the lives of the developmentally disabled. The other children in the family who do pass through these often feel guilty when they feel their parents' happiness for them and sorrow for the other.

Institutionalization, which may have been avoided during the parents' lifetime, may become an issue with their advancing age, illness or death. The remaining siblings are left to incorporate the retarded (now adult) member into their household or face the guilt of doing what their parents were unable or unwilling to do. Conflict results when one knows that it is best to ive in as "normal" a living situation as possible but the questions arise, "normal for whom?" and "at what sacrifice?"

Legislation and community activism are needed so that there are more resources. The Bold New Approach of John F. Kennedy in 1963 set the stage for programs for the mentally retarded (Schreiber, 1970). Group homes, hostels, day care centers, schools, workshops, counseling services and respite care are needed to offer families support and relief in their care.

Assessment

Psychiatric nurses are in a unique position to offer services to these families. By virtue of our early, basic educational experiences we have a good background in the physical, psychological, socio-cultural and spirtual needs and experiences of families. Because we have worked with people of all ages we have parameters of expected developmental progression for individuals and families. With our advanced specialist education we have the knowledge and skills necessary to conduct thereapuetic intervention in complex family systems.

COPING COMPETENCIES FOR ASSESSMENT

1. Are basic survival and safety needs attended to for each family member?

2. Is there adequate food, shelter, clothing, money and health care?

3. Is the home running smoothly and effectively?

4. Is each family member able to conduct his private and public life with some degree of age appropriate satisfaction and success?

5. Do people come to the house and share family social activities? Does the family accept outside invitations?

6. Can subsystems spend time alone and apart from family as well as within the family?

7. To what degree does the handicapped child predominate family life?

8. Do family members show evidence of physical or psychological symptoms?

9. Are family members comfortable with negative and positive affects toward each other?

10. Is there flexibility in relating to a retarded family member?

11. Does each family member have individual sense of identity different from and separate from relationship to developmentally disabled member?

12. Can family members talk to each other and outsiders about their family situation or is it guarded with secrecy and shame?

13. General family tone - anxiety? depression? sense of humor? optimism?

Summary

In summary, families of the developmentally disabled need to be looked at in terms of their system wholeness. The family's life cycle intersecting with the needs of the special or different family needs to be identified. Interacting elements of the subsystems have unique concerns and coping styles. Compassion, understanding, knowledge and resources need to be offered to assist these families' movement in the direction of openness, growth and health.

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FINAL SESSION: THE PARENT PERSPECTIVE

Cory Moore

Betty Pendler's notes comment on the ambivalence felt by parents toward sibs: we want to know their feelings and yet somehow we're afraid to hear the messages. Perhaps wer worry that their feelings may mirror ours which are not always positive and helpful; we don't welcome another problem to cope with ourselves; too often we lean on sibs for strength and for help.

What, then, do we need as families, as parents and siblings? What we need first are the direct support services that will make life palatable and as free from worry at it can be -- quality group homes, community supports, citizen advocacy groups, information and referral service, easy links to resources.

We want our nonhandicapped children free from the direct burden of responsiblity when wer are dead, though in time we do come to realize we cannot always relieve those children of the normal and emotional responsiblity. My own understanding cam recently and it was a profound revelation. Many of you have heard me comment on this experience in previous workshops. For those of you who haven't, let me share my twenty year old daughter's comment when I called her to tell her that her 18 year old sister who has multiple handicaps will be moving from our house into a group home -- quality -- this summer. "Mom," she said, "I know you and Dad have always said that Leslie is not my responsibility, but, Mom, Leslie has always been my responsibility." What enormous, overwhelming feeling siblings live with and don't always share -- even in families where that sharing I though was fully allowed.

For coming generations, then, let there be honest communication between parents AND sibs -- AND professionals. Our egos should not always get in the way of hearing each other's important messages. Families and sibs should not be perceived as needing treatment but rather should be seen as experts concerning the child they live with. Professionals need to help parents listen to the siblings, respect their needs, and understand what they want and see as appropriate. Another story I told in my workshop: a friend of mine was coming down on the side of lower expectations regarding discipline of her child who is retarded when she was brought to new awareness by her older daughter who told her emphatically, "Mom, I know what's best for Susan. After all, I've lived with her ten of my fourteen years, you've only lived with her ten of your forty-six." Sibs do have important and unque perspectives to share.

My biggest hope for sibs in the years to come is that society will continue along the paths, happily now begun, toward destigmatization of those people perceived as "different." What we all need is attitudinal change, acceptance of people as they are with supports in place to help them become all they can be, interactive activities, open schools and neighborhoods, an affective curriculum concerning handicapping conditions in all our schools. Much is being done currently; let's all continue to encourage its extension.

Finally, since I am representing the parent perspective today, let me beg forgiveness from the siblings for double standards we raised you with, the enormity of our expectations -- both voiced and unvoiced. Siblings are very special people; we parents need to let them know that more often. We need, also, to leave to you the directions and paths you will want to choose and the hope we can be strong enough to help you along the way.

I was delighted to be part of these two days. Thank you for enlarging my perspective.